

**Evaluation of the development needs of palliative care
programme managers in the context of providing quality
palliative care to increasing numbers of patients in Kenya,
Malawi and South Africa**

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Abstract

Introduction

In recent years the focus of hospice programmes has had to evolve from caring for terminal cancer and motor neuron disease (MND) patients to include patients with HIV/AIDS and TB, because of the growing number of patients needing care as a result of the HIV/AIDS and TB crises. This has significantly impacted hospice programmes as they have to care for far greater numbers of patients. Although some of the hospice patients with HIV/AIDS and TB are in the terminal phase, there are increasing numbers of patients who require chronic and palliative care and their needs are quite different from patients with terminal cancer or motor-neuron disease.

A series of regional workshops was held by the Hospice Palliative Care Association (HPCA) in 2009. Palliative care programme managers reported during the workshops that they felt ill-equipped to manage these bigger and more involved programmes and that their lack of skill impacted on the quality and reach of care that can be given.

Methodology

The study is a cross-sectional, qualitative assessment of the current development needs of professionals within the hospice settings in Kenya, Malawi and South Africa. The study comprised two phases. Phase one comprised six focus group discussions with palliative care programme managers from hospices in Kenya, Malawi and South Africa. Participants were recruited using purposive sampling. In Phase two a questionnaire was developed from the themes identified in the part one

focus groups. This was distributed to all [entire population] palliative care programme managers in Kenya, Malawi and South Africa.

Data management and analysis

Data from the study was thematically analysed. The thematic analysis was done by reading through the narrative data that was collected from the focus group discussions and identifying common themes that emerged. The themes from the first phase enabled the researcher to develop questions for phase two of the study, the questionnaire. The questionnaire was loaded onto a survey website (Survey Monkey), and participants completed the questionnaire on line. Analysis for this section of the research was done automatically by the survey website.

Ethical considerations

All participants were given sufficient information about the study to make an informed consent. They were informed that they could refuse to participate or withdraw at any time without threat of reprisal. Even though participation was unlikely to cause discomfort or distress, provision was made to provide counselling should a participant experience any distress during or due to the study. The safety and protection of participants was further ensured by the fact that the author followed ethical practices as stipulated in the Helsinki declaration and the HPCA and the University of Cape Town (UCT) ethical guidelines. Ethics approval was obtained from the UCT Human Research Ethics Committee, the HPCA ethics committee as well the Human Research Ethics Committees in Kenya and Malawi prior to commencement of the study.

Findings

This study intended to identify the professional development needs of palliative care programme managers in hospices in Kenya, Malawi and South Africa. The findings reveal that palliative care programme managers have professional development needs related to their management function that include an on-going professional development programme, training in management functions and palliative care training for non-clinical managers and staff.

Conclusion

The results of the study will be used to develop a training curriculum and training material for palliative care programme managers as well as a template job profile for the palliative care programme manager position.

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Declaration

I, Susan McGarvie, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and have used the Vancouver system of referencing. I declare that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Definitions of terms and abbreviations

- HPCA: Hospice Palliative Care Association of South Africa.
- Palliative Care Development officer (PCDO): HPCA has PCDO's in each province in South Africa who assist hospices with development in order to achieve and maintain a set of standards that have been developed by HPCA to ensure that hospices are providing optimal care for patients and using funding responsibly so that they will be sustainable organisations.
- Palliative care programme managers (PCPM): Professional person with designated responsibility of managing the care operations of palliative care programmes in hospices.
- CIDA: Canadian International Development Agency.
- Member hospice: Hospices who are affiliated with a national standards association such as HPCA.
- DPOWMF: The Diana Princess of Wales Memorial Fund
- KEHPCA: Kenyan Hospice Palliative Care Association
- PACAM: Palliative Care Association of Malawi
- NPO: Non-profit organisation
- MND: Motor Neuron Disease
- WHO: World Health Organisation

Chapter one

Introduction

Background to the study

The healthcare climate in Africa has been severely impacted by the rising incidence of HIV/AIDS and cancer. Avert International report that due to the decreasing HIV mortality rate, there are increasing numbers of people in Africa living with HIV/AIDS.⁽¹⁾ This means that there are ever-growing numbers of patients who require healthcare, especially palliative care, in remote rural geographical areas that have little or no infrastructure and healthcare resources. According to Harding et al hospital infrastructure simply cannot manage the extensive burden of HIV/AIDS.⁽²⁾ The problem is compounded by the fact that in most countries in Africa, the relevant authorities do not have the financial or human resources to provide the health care services that are required as a result of the increasing numbers of patients. Johnson reports that although the South African Government is doing extensive work in preventing and managing the results of HIV/AIDS, Non Profit Organisations (NPO's) are doing the greater part of the routine work involved in caring for HIV/AIDS patients.⁽³⁾ In their study, Harding et al found that, national strategies for terminal and palliative care were, in most cases, non-existent.⁽²⁾ Non-profit Organisations such as hospices have therefore taken on a major role in the provision of palliative care in Africa, because public sector outreach programmes do not function optimally due to a lack of funding for transport and other programme related costs.⁽⁴⁾ Johnson points out that the South African healthcare system does not have the capacity to service rural and impoverished areas and the task has therefore fallen to HIV/AIDS non-governmental organisations working in those areas.⁽³⁾

The Hospice Movement

For the purposes of this study, the term hospice is used to describe those organisations that provide palliative care to patients with life-limiting illnesses.

Hospices provide palliative care to patients in their homes and/or in an in-patient setting. Because hospices have developed and evolved in response to the needs of the communities they serve, their programmes and objectives may vary slightly from organisation to organisation. National healthcare strategies and funding requirements may also influence the nature of the programmes being run by different hospices in different countries and regions within countries. The size and capacity of individual hospices also varies depending on the resources of the organisation and the needs of the community. Most hospices are Non Profit Organisations and provide their services free of charge.

In Kenya, Malawi and South Africa there are palliative care associations to which hospices can choose to belong. Membership to HPCA (Hospice Palliative Care Association of South Africa), KEHPCA (Kenya Hospice Palliative Care Association) and PACAM (Palliative Care Association of Malawi) is voluntary, but it does have benefits such as increased access to funding and support. The following table indicates the number of hospices affiliated with the hospice associations in each country:

Fig 1.1 Number of hospices affiliated with the hospice associations of each country

Country	Kenya	Malawi	South Africa
Name of association	KEHPCA	PACAM	HPCA
Number of affiliated hospices	31	20	189

Doyle et al state that palliative care developed from hospice care.⁽⁵⁾ Hospices have taken on a major role in the provision of palliative care in Africa and they are finding that their role in providing palliative care has shifted significantly with the introduction of HIV/AIDS and, more recently, TB patients to the hospice programme. This introduction has meant that the hospice programme has had to expand to include a broader circle of care, which now also includes preventative care as well as chronic care for patients living and dying with HIV/AIDS and TB.

Comparable to the Government Health departments in Africa, hospices also function with limited resources and the most significant limitation is that of professional healthcare staff. This is due to poor salary structures for healthcare personnel in Africa and the working environments are unsatisfactory and unpleasant.⁽⁶⁾ Many of the few who choose to qualify in the healthcare disciplines choose to find work in first world countries. According to the World Health Organisation (WHO) the departure of healthcare professionals from Africa, has intensified the impact of the HIV/AIDS crisis in Africa.⁽⁶⁾ The lack of resources and professional staff (doctors, nurses and social workers) in this climate of ever-growing need for healthcare means that the capacity of the hospices is being stretched to its limits. HPCA has addressed this problem by designing a patient care model in which most of the direct hands-on care is provided by non-professional, trained community caregivers who are supervised by professional healthcare staff. In 2009, HPCA conducted regional audits related to funding that they had received from Canadian International Development Agency (CIDA). During these workshops palliative care programme managers working in hospices in South Africa indicated that they are ill-equipped to manage these growing and evolving palliative care programmes and that this impacts on the quality of care that can be provided.

It is intended that the assessment of professional development needs carried out for the purposes of this study will inform the development of a professional development programme that is ideally suited to meet the needs of palliative care programme managers working in hospices in Kenya, Malawi and South Africa. Palliative care programme managers are professional staff members who manage the care operations of the programmes being run by the organisations. There are varying levels of palliative care programme managers from a professional nurse or social worker who manages a team of lay caregivers up to a manager who manages and coordinates all the care programmes being run by the organisation. This role differs from the role of the hospice manager who would manage the overall organisational operations.

Several previous studies have highlighted the need for assessment prior to training and development. According to Hicks and Thomas it is prudent to base training and development programmes on relevant empirical data so as to maximise their impact and ensure efficient use of resources⁽⁷⁾ and Roche, Pidd and Freeman agree that training should be based on a needs analysis of the intended trainees.⁽⁸⁾ The author therefore intends to assess the specific professional development needs of palliative care programme managers in hospices so that HPCA can develop a training curriculum and training material based on this needs assessment.

According to WHO and researchers such as Buchan and Aiken the shortage of healthcare professionals is proving to be a major barrier to achieving effective healthcare systems.^(9, 10) Because of the needs across Africa, it was decided that this project would include two other African countries. This inclusion served to identify if professional development needs varied across national borders in Africa and whether training material that was subsequently developed would be appropriate and useful in other African countries.

Hicks and Thomas state that successful professional development programmes should be based on skills audits ⁽⁷⁾ therefore, it was anticipated that, by accurately determining the professional development needs, an effective and meaningful curriculum and training material could be developed. The author believed that providing palliative care programme managers with the skills to manage their programmes more efficiently, is one way in which the reach and quality of palliative care provided in hospices in Africa can be expanded.

Problem statement

A global need to augment clinical management skills in health care is supported by Buchan and Aiken and the WHO, who state that countless countries need to review and improve their staff planning process to include needs assessment and evaluation if they are to increase capacity.^(9, 10) This need in hospice programmes in South Africa has been corroborated in the aforementioned regional workshops

conducted by HPCA during 2009. These workshops were held in each province in South Africa and attended by palliative care programme managers from hospices in the province. The workshops focused on identifying the challenges that palliative care programme managers are experiencing in the field. The palliative care programme managers reported that they do not have the skills required to effectively co-ordinate the palliative care programmes for which they have been made responsible, which left them feeling inadequate and emotionally stressed. This may result in poor leadership and less than optimal use of scarce professional resources both of which are crucial for programmes to effectively address the overwhelming need for palliative care that has arisen because of the HIV/AIDS epidemic. According to De Cock et al Sub-Saharan Africa has a disproportionate ratio of HIV/AIDS infections, disease and deaths as well as orphans and vulnerable children to the population in the area.⁽¹¹⁾ The WHO report that Africa has 3% of the world's healthcare workers and commands only 1% of the world's health expenditure ⁽⁶⁾ and in another WHO report it states that due to shrinking health workforces, uneven distribution and the so called, *brain drain* from Africa, Human Health Resources are as much a challenge now as they were in 2006.⁽⁴⁾

Concluding comments

This study has been done based on information gleaned by HPCA during regional CIDA workshops in which it was noted that palliative care programme managers feel ill-equipped to manage their ever evolving programmes. This study has evaluated the professional development needs of palliative care programme managers in the context of providing palliative care to growing numbers of patients. This has been done by means a two phase study which undertook focus group discussions as well as an on-line survey. The findings were disseminated to all participating associations and their member hospices. These findings were also presented at the HPCA national conference in Cape Town in 2012.

In the following chapters a literature review, a detailed explanation of the methods used to collect, store, analyse and disseminate data, a review of ethical

considerations, a discussion of the results as well as the recommendations and a description of the outcomes of this study will be presented.

Chapter two

Literature review

Introduction

Research theorists propose that research projects have no relevance if the researcher cannot place their study within the context of existing research. They recommend therefore, that previous work be reviewed and evaluated so that new research augments existing research.⁽¹²⁾ This literature review is a traditional literature review which serves to place this research within the context of current and past research. According to Cronin et al a traditional or narrative literature review should afford readers a thorough understanding of the context of current knowledge and emphasise the significance of new research. They add that a good literature review can instigate new research initiatives which fill existing gaps or inconsistencies in the current literature.⁽¹³⁾ The author intends to present the literature in such a way as to illustrate that there is evidence that there is indeed a shortage of palliative care programme managers and that the roles of palliative care programme managers have changed. The author also intends to present the literature so as to support the hypothesis that this enquiry into the professional development needs of palliative care programme managers is indeed necessary.

In addition, this literature review has been done to establish the context of palliative care programme managers working in hospices in Kenya, Malawi and South Africa. It may be assumed that these healthcare professionals work in an environment in which resources are limited and needs are ever increasing, but the author wanted to find literature that would support this assumption.

Search strategy

The search strategy involved an initial search of topics such as: 'task shifting', 'the role of the caregiver', 'professional healthcare personnel shortages', 'mentorship and coaching in palliative care' and 'development needs of professional healthcare personnel in home-based-care settings'. Searches were done using databases such as EBSCOhost (Including: CINAHL, Medline, Health Source, PsychARTICLES, PsychINFO and SocINDEX) and Google Scholar and personal textbooks. As the research progressed and evolved further search terms were added: keywords such as professional development, training and palliative care. Internet search engines such as Google and Bing were also used to find information related to the state of health care in South and East Africa and the HIV/AIDS, TB and cancer statistics in South and East Africa. The WHO website provided information in respect of the current health situation in Africa and human resources for health.

The above searches focused on material published between 2001 and 2010 so as to ensure relevance and currency of data. Older publications were used in cases where pertinent research was done and published prior to 2001 with no subsequent publications of similar or related data.

Findings of the literature review

There are several main issues that stand out in related current available research: the growing shortage of professional healthcare personnel, the changing roles of professional healthcare personnel, mentorship and coaching, and training.

Shortage of professional healthcare personnel

The shortage of professional healthcare personnel is a global problem. The WHO reported that the shortage crisis had the potential to deepen in the coming years.^(6,9) According to WHO reports, there were 2.3 healthcare workers per 1000 people in

Africa compared to the global average of 9.3 per 1000.⁽⁶⁾ The shortage of professional healthcare personnel is widespread and not exclusive to Africa, but the current climate of impoverishment and widespread disease in Africa does highlight the extreme nature of the problem, especially in the hospice setting. Buchan and Aiken report that the causes of the shortages of healthcare personnel can be related to inadequate policy development and maintenance regarding staff planning, recruitment and retention of staff as well as poor human resource management with regard to staff allocation, career support and incentivising. These authors go on to report that nursing shortages are more than just an organisational problem as they affect healthcare in its entirety.⁽⁹⁾

The WHO has reported on the shortages of professional healthcare personnel at a global level which is compounded by the HIV/AIDS crisis and poverty in Africa, and it purports that it has long been known that health systems and services can only be optimally strengthened by developing and strengthening the health workforce.⁽¹⁴⁾ The WHO Human Resource for Health (HRH) commission was set up as a part of the strategy to improve healthcare at a global level.⁽¹⁴⁾ The HRH report for 2011 states that in recognising, the need to develop strategies to strengthen the health workforce to strengthen health service systems, it is also recognised that there is a need for improved information and data to inform policy development which has led to the creation of the HRH observatories in various countries and regions.

The African branch of HRH has commissioned country profiles that outline the health profiles of the countries including the human resources in health in those countries. Both Kenya and Malawi have reports for 2009 and 2011 respectively. The Kenyan report shows that there has been a decline in the number of Ministry of Health doctors and nurses between 2004 and 2008. The number of doctors there declined by 6% and the number of registered nurses declined by 17%. Adjunct health professions such as social work, psychology and physiotherapy did not feature on this table at all.⁽¹⁵⁾ The Malawian report shows increases across the board in the number of healthcare professionals between 2004 and 2009, but these numbers remain very low in relation to the population. According to this report, there were

7.33 clinical officers per 100 000 in 2009 and 36.83 nurses per 100 000 and again, this table did not reflect social workers who are an integral part of the palliative care team.

The third country in this study, South Africa, did not have a comparable profile on the HRH website, which outlined the current health labour force set against a target labour force for health. However, a similar report written by Liese and Dussault on *The state of Health workforce in Sub-Saharan Africa* from 2004 shows that the number of doctors and nurses were, then, 25.1 and 140 per 100 00 population. The same report put the ratios of doctors and nurses in Kenya in 2004 at 14.1 and 108.0 per 100 000 respectively.⁽¹⁶⁾ Both these countries appear to have significantly higher numbers of doctors and nurses per 100 000 population than Malawi and considering that Malawi is a poorer country economically, this is understandable, but it is also that much more worrying as a greater degree of poverty is likely to equate to a greater degree of need.

The following table summarises the statistics presented in the above mentioned reports. These statistics have been taken from different reports at different times and do not therefore, give an accurate comparison of doctor and nurse ratios per 100 000 population in Kenya, Malawi and South Africa. However, no current literature which directly provides for this kind of comparison between the three countries could be found at this time.

	Kenya	Malawi	South Africa
Clinical officers/doctors	14.1	7.3	25.1
Nurses	108	36.83	140
Year of publication of statistics	2004	2009	2004

Fig 2.1 Ratio of Doctors and Nurses per 100 000 people in Kenya, Malawi and South Africa (15, 16)

In their report, Liese and Dussault also highlight current issues that may impede the achievement of the Millennium Development Goals, which is a set of goals that were accepted by the international community in order to show commitment to improving the quality of life for people in developing countries.⁽¹⁶⁾ According to their report the significant problems which lead to the lack of a stable health workforce is recognised as a major barrier to effective health services and has come to be dubbed *The African health workforce crisis*.⁽¹⁶⁾ In addition to increasing populations, the increasing incidence of HIV/AIDS and the present economic and political issues in Africa, this report examines the migration of professional healthcare personnel out of Africa. This “brain drain” has become a controversial issue in healthcare in Africa and indeed, the world.^(16, 17) These authors report that the health workforce has become worryingly demotivated which is resulting in their migration to more developed countries. These countries have health workforce shortage problems of their own and therefore a great number of job opportunities for migrants.⁽¹⁶⁾

This *brain drain* has financial implications over-and-above the impact to healthcare in Africa and attempts have been made to prevent this migration by limiting the opportunities abroad. In 2001 The Mercury newspaper published an article which reported that Nelson Mandela had pleaded with Britain to stop recruiting healthcare professionals from South Africa ⁽¹⁸⁾, but it can be argued that this attempt infringes on the rights of people to better their quality of life and thereby directly contravenes the

Millennium Development Goals. It makes more sense to spend time and energy to create an environment at home which is more attractive so that these healthcare professionals have an opportunity to remain in Africa, because most of those who choose to leave do so because of the limited opportunities for career development in environments that are stressful and dangerous as reported above.

According to Buchan and Aiken, it is very difficult to determine optimal average ratios of healthcare workers to population as there are a number of factors that need to be taken into account and comparisons are usually made between countries of similar development.⁽⁹⁾ This means that although the above mentioned reports and literature clearly support the notion of a shortage of professional healthcare personnel, the diversity across Africa, within African countries and within different health sectors makes it difficult to determine ideal staff/patient ratios and this makes it difficult to ascertain the actual extent of the crisis.

Task shifting/role transition

The roles of professional healthcare personnel have changed significantly over the last few decades and a new cadre of healthcare worker has developed in response to the HIV crisis and the shortage of healthcare professionals in Africa. This created the role of the caregiver or community caregiver which takes the form of non-professional people living in the communities who have had basic training to provide care for patients in their homes.⁽¹⁹⁾ This means that the role of the professional has changed from the provision of care to the management of teams of non-professional caregivers. According to Lehman et al; in Africa, task shifting and/or role transition has occurred in response to the healthcare crisis which has developed due to the HIV epidemic. This has created an increasing need for healthcare services paralleled with the severe shortage of healthcare workers in healthcare departments on the continent. ⁽²⁰⁾

Holt refers to role transition or task shifting as a continuous developmental process or a change caused by a specific event such as increased job responsibility, promotion or transfer and adds that government policies have highlighted that quality care is dependent on the changing roles of healthcare workers.⁽²¹⁾ The WHO report that task shifting can significantly strengthen existing healthcare services, improve the quality of services and expand the reach of services into more rural areas that may otherwise, not have received services. These advantages are dependent on optimal implementation policies and procedures and task shifting alone will not solve the problems related to healthcare personnel shortages.⁽²²⁾ The WHO also acknowledges that task shifting between health care workers and expanding the clinical team is an effective short-term solution, to relieve human resource limitations in settings with low resources, and that additional health system strengthening measures will need to be employed in the long term.⁽⁶⁾ Phillips, Zachariah and Venis support this theory by saying that task shifting is only effective as a part of an overall human resources strategy.⁽²³⁾

According to Chan, role changes and restructuring that is done to improve the quality of care places increasing pressure on healthcare personnel.⁽²⁴⁾ Glasberg et al found that due to constant changes and rationalising, healthcare personnel experience increased burdens and obligations.⁽²⁵⁾

Although there is literature to support the role of task shifting as a tool to strengthen healthcare in Africa, there is also literature which recognises the limitations of task shifting. Berer points out that in many cases lower cadres of healthcare personnel are expected to take on more advanced roles in healthcare service without adequate preparation, training, support or remuneration.⁽²⁶⁾

Holt, Chan and Glasberg support Berer's findings and state that it is known that role change is stressful and places increasing pressure on healthcare personnel and yet it is frequently not coordinated and for those involved there is an inadequate provision of support.⁽²¹⁾ Thorpe and Loo found that the head nurse position has evolved to address managerial versus clinical roles and functions, titles and job

descriptions have been revised to support changing responsibilities, but very often the new roles and responsibilities remain implicit.⁽²⁷⁾ This means that healthcare personnel are expected to work in positions of ever evolving responsibilities with little or no guidelines of the expectations and it would appear that little or no support or training is given to help develop these professionals so that they can fulfil the requirements of these evolving positions.⁽²⁷⁾ Chan contributes to this argument by stating that the healthcare industry is challenged by the need to support clinical staff during periods of change.⁽²⁴⁾ Glasberg proposes that this lack of support during the extraordinary frequency of change experienced by healthcare workers and the stress that it causes is a major source of burnout.⁽²⁵⁾

Nurses and other professionals who function as palliative care programme managers within the hospice environment in South Africa have identified a need for better management skills training to help them to cope with the shift in their role from hands-on patient care to patient care management. The WHO reports that a more direct investment in the training and support of healthcare workers is one of the requirements for tackling the crisis.^(6,27) In order to address this need to invest in healthcare staff, the WHO has established The WHO Human Resources for Health commission, because it is acknowledged that in order to strengthen and improve health services, it is imperative to strengthen health human resources.⁽²⁸⁾

It is evident from the foregoing literature that extensive research has been done regarding the extent and frequency of task shifting as well as the implications thereof. The author therefore asserts that it is reasonable to assume that palliative care programme managers experience similar task shifting and the pressures and stresses that accompany it. This study will identify the professional development needs and potential support systems which will strengthen palliative care programme managers' ability to cope with task shifting. This will enable palliative care programme managers to support the strengthening of health systems in Africa.

Mentorship and coaching

This literature review revealed that although there is a wealth of data regarding coaching and mentorship programmes in the corporate and business sector, especially related to leadership, there is very little evidence of research that has been done in the Health sector in Africa and even less in the NPO sector in Africa. The following section will highlight research which has been done and will identify the gaps and opportunities for further research in this context.

The WHO has identified that health professionals who work in remote or rural areas suffer from both professional and personal isolation. The WHO also recognises that this isolation is more pronounced in the developing countries of sub-Saharan Africa and South Asia, where the great majority of the population lives in rural areas.⁽⁴⁾ Furthermore, the WHO has established that in order to strengthen healthcare systems, it is imperative to strengthen the health workforce and mentorship programmes are an effective way to strengthen this workforce ^(6,29) and Johnson et al present a case study that identifies the need for collaboration between national HR development policies and strategies and NPO's. This study highlights the work of NPO's in HIV/AIDS and the need for mentorship and coaching amongst healthcare professionals working in the HIV/AIDs environment. It also highlights the increased burden which HIV/AIDS places on the national workforce.⁽³⁾

The above-mentioned literature would suggest that there is a key role for mentorship and coaching programmes in the health workforce and based on the successes of mentorship and coaching programmes in other fields on other continents, it is assumed that these programmes would be effective in the NPO healthcare sector in Africa. The following sections will show that there have been successful programmes in this niche sector and in the healthcare sector in Africa in general, but the number of published studies which have been done are limited and leave room for further investigation. Henochowicz and Hetherington have studied the use of coaching and mentorship in the healthcare setting and their findings suggest that although these

approaches to professional development prove very successful, they are under-utilised.⁽³⁰⁾

In 2001, HPCA started using a mentorship programme to help them expand the reach and quality of palliative care in South Africa. Today, HPCA field staff members, known as Palliative Care Development Officers (PCDO's), run mentorship programmes with hospices in which they collaborate with hospice management to draw up a development plan with goals and targets for each year. They then follow up with site visits and electronic contact to monitor progress and offer support to the organisations and their management teams and staff. In addition to the HPCA field staff, hospices which have benefited from mentorship from HPCA mentorship have gone on to mentor new and developing hospices with great success. The impact of this mentorship programme was investigated by Defilippi and Cameron and they found that the mentorship is very successful in development programmes.⁽³¹⁾ And they concluded their report by saying that the HPCA mentorship programme illustrated that "mentorship can be widely applied if the necessary infrastructure is sustained. It is anticipated that the HPCA mentorship program will continue to provide significant, long-term benefits for growth and development of palliative care for both individuals and organizations across South Africa, Africa, and potentially Worldwide".⁽³¹⁾ As mentioned previously, this appears to be the only or one of very few research studies that has been done to evaluate the impact of mentorship in the NPO healthcare sector in Africa and even though this programme has proven to be a success, there is definitely scope for further research in this area. In particular, a study which evaluates the long-term sustainability of the results of mentorship and coaching programmes in the healthcare and NPO context in Africa.

More generally, in healthcare, Dorhn et al reports that a very successful mentorship programme was implemented by Columbia University in 2006 in the Eastern Cape and they propose that similar programmes should form part of the plan to scale-up the HIV/AIDS strategy.⁽³²⁾ More recently, research has been done in Uganda which highlights the success of a mentorship programme among nurses in Uganda. Anatole et al report that they have succeeded in implementing a district-wide, nurse-

focused mentorship program that addresses quality of care at both individual provider and systems levels.⁽³³⁾ According to Istre, mentoring is essential to promoting quality primary healthcare in South Africa.⁽³⁴⁾ From these studies, there is evidence that mentorship proves to be valuable and successful in human resource development and support programmes, but the number of studies that have been done within this context is also limited. These studies measure the effects of mentorship and coaching over a relatively short period and the sustainability of these successes is therefore not evident. This can be seen as a gap which requires further research.

Several of the recent WHO reports for health in Africa recognise that the development of the professional health workforce is imperative to reaching the Millennium Development Goals.^(28, 6, 10) As mentioned above, this review of the literature yielded no evidence of any studies that have been done to determine the impact of mentorship programmes on healthcare professionals in the hospice setting in Africa. According to Murphy, mentors are critical to successful adjustments to change in the work setting.⁽³⁵⁾ Mentorship programmes, which facilitate personal growth and development, have been developed for Human Resource Management and the WHO seems to have recognised the fact that Healthcare professionals working in the current African context need support if they are to be a sustainable resource for healthcare going forward. The report written for: *Outreach Services as a Strategy to Increase Access to Health Workers in Remote and Rural Areas* states that those working at ground level in remote and rural communities need to be afforded every available resource for support.⁽⁴⁾ Leners et al support the WHO's standpoint by suggesting that in the current situation of limited funding for healthcare and workforce shortages, improving the work environment and support structures for healthcare workers is a means to support the workforce and strengthen healthcare structures.⁽³⁶⁾ Globally, mentorship has been advocated as a means to increase retention in healthcare. Leners et al contend that staff retention strategies would benefit from formal mentorship programmes.⁽³⁶⁾

Overall, the literature reviewed on mentorship and coaching proposes that they are a very important component of professional development and that there are significant gaps in current literature. The author proposes that although the results from these

studies are very positive, they do not give evidence of the long term sustainability of the effects of the mentorship and coaching programmes.

Training

Because literature related to adult education and workforce training of palliative care programme managers in Africa could not be found, literature related to adult education and workforce training in healthcare in Africa has been reviewed.

Roche et al propose that adult education and the training of staff members within organisations has evolved significantly in the last few decades and this is due in part to the realisation that, for workforce development to be effective, training needs to be supported on many levels.⁽⁸⁾ They add that there are a number of factors that are involved in workforce development that go beyond traditional theories of training and points out that adult learning theory suggest that adults have specific needs that should be met in order to enhance their learning capacity.⁽⁸⁾ The author believes that these theories are particularly important to this research as the need to optimise on training and development programmes is imperative in the NPO setting.

The author was particularly interested in findings by Lester et al which supported the fact that training needs to be linked to coaching and mentorship programmes if it is to be successful. Lester et al reported that organisations that take advantage of individualised mentorship will see increased responses to training and mentorship programmes.⁽³⁷⁾

The literature that is available on training and training needs assessment in Africa asserts that there is a critical need for training to be specific to the learners needs and that training needs to be supported by mentorship, coaching and/supervision programmes. These programmes will augment the acquisition and retention of knowledge as well as the learner's ability to apply the acquired knowledge. As in other sections of the review, there is little evidence of research that has been done in the author's specific context.

Conclusion

A review of the literature indicates that although research has been done to establish the importance of professional development, which includes coaching, mentorship and training, in many industries in the first world context, very little research has been done to establish the need for such programmes within the hospice context in South and East Africa. No published work has been found looking specifically at the development needs of palliative care programme managers working in hospices in South East Africa. The literature has however, highlighted a need for mentorship programmes and development programmes for healthcare professionals and purports their effectiveness, but as yet, these do not reflect the long-term results of these interventions.

The current literature also highlights that training and development programmes should be preceded by an evaluation of the current needs of the training participants, which places this study in an ideal position to fill a gap in current literature.

Chapter three

Research Methodology

Introduction

Research methodology includes both the research design and the research methods used during the course of a study. This chapter will describe and justify the research design and the research methods used for this study by discussing the aims and objectives, the research design, sampling, the research process, data and the ethical considerations.

Aims and Objectives

Aims:

- The overall aim of this research was to identify the development needs of palliative care programme managers in hospices in Kenya, Malawi and South Africa.

Objectives:

- To assess pre-service and in-service preparation for support of community care givers.
- To identify the elements required to provide supervision of community caregivers.
- To assess the patient care manager's perception of the essential elements of quality palliative care.
- Assess the resources with regard to mentorship of the patient care managers

Research design

This is an exploratory, mixed method study which was done in two phases. Exploratory studies are used to make initial enquiries into unfamiliar areas of research.⁽¹²⁾ This study explored the current professional development needs of patient care managers using both qualitative and quantitative research methods. As noted in the literature review, there has been very little research done in this specific context and an exploratory study is therefore appropriate.

Because the author intended to explore current potential development needs of palliative care programme managers in hospices in Kenya, Malawi and South Africa she decided to use a qualitative method for phase one of the study as this would allow her to study the issues in depth with openness and detail as themes began to emerge.⁽¹²⁾ This interpretive method is appropriate to this study, because the author wishes to establish the internal experience of healthcare professionals and their development needs set against the background of their external reality of working in hospices in Kenya, Malawi and South Africa.⁽¹²⁾

Sampling

Marshall describes three approaches to sampling for qualitative research namely: convenience sampling, purposive sampling and theoretical sampling.⁽³⁸⁾ Purposive sampling was chosen, because it has been identified that purposive sampling approaches are intended to enrich the researcher's understanding of the experiences of the target group.⁽³⁹⁾ Purposive sampling was also chosen in order to ensure that the focus group participants were able to provide the greatest insight into the research question.⁽³⁹⁾

For this study, the population to be studied was very specific and relatively small as there is only one palliative care programme manager per hospice and there are a finite number of hospices in each country. This was another consideration in the decision to do purposive sampling. Palliative care programme managers from

hospices in pre-identified regions were invited to the focus group discussions. These invitations were done through the Palliative Care Development Officers (PCDO's) in each province and the relevant Hospice managers. Palliative care programme managers from eight to ten hospices were invited to the regional focus group discussions.

In phase II, there was no sampling process as the survey was sent to the entire population of palliative care programme managers.

Sampling for Phase I:

The specific sampling process for the pilot focus group and the remaining focus groups is discussed in more detail below:

Sampling for the Pilot Focus Group Discussion: Eastern Cape, South Africa

Seven hospices from the Eastern Cape were invited to the pilot focus group discussion held in the Eastern Cape. Hospices in this province widely scattered over this rural province. This meant that only three of the invited hospices were able to send participants. This focus group comprised five participants. Other contributing factors to the low number of participants were: unforeseen staff absenteeism and an inability for smaller hospices to release staff.

Sampling for remaining Focus Group Discussions

The sampling procedure mentioned above was used for all the focus group discussions: the PCDO's in the relevant regions were asked to approach hospice managers in their area and ask them to nominate those palliative care programme managers who would be appropriate and available to attend the focus group

discussions. These palliative care programme managers were then invited to attend the focus group discussions held in their region.

At the focus group discussion held in Johannesburg there were 8 participants and in the Western Cape all the invited hospices sent participants and some of them more than one, which meant that that discussion group had 13 participants. In Malawi, two focus group discussions were held with 8 and 7 participants respectively while in Kenya; one focus group discussion was held which was attended by 8 participants. Participants from the different regions in the countries were invited so that needs could be assessed across the geographic areas of each country.

Sampling for phase II: the survey

There was no sampling process for phase II of the study as the entire population was used, i.e. all palliative care programme managers from all member hospices, approximately 200 participants, were invited to complete the survey and all returned questionnaires were analysed.

Research Methods

This study was done in two phases. Phase I of the study was done by means of focus group interviews and phase II was done by means of an online survey set up on a web-based survey site called, Survey Monkey.

Phase II of the study was done to validate the data gleaned from the focus group discussions in phase I. The author wanted to ensure that needs identified in the focus group discussions were shared by the rest of the population of palliative care programme managers in hospices in Malawi, Kenya and South Africa.

Phase I: Focus Group Discussions

Focus group discussions were chosen, because the author wished to identify a collective need rather than the individual development needs of professional healthcare personnel. According to Terre Blanche et al, the focus group allows the author to gain access to an inter-subjective experience.⁽¹²⁾ The author does however acknowledge that some people feel more comfortable on a one-to-one basis and that those individuals may be reluctant to participate in the group discussions, which may impede data gathering in the focus group discussion context. For this reason, the author made sure that the participants knew what to expect before they agreed to come to the focus group discussions (see the information sheet in addendum B.) and that the facilitator was very careful to put everyone at ease before and during the discussions. The facilitator also made sure that the participants knew that this was a data gathering exercise and that there were “no wrong ideas”. She made it very clear that the author was interested in their personal experience and this seemed to be effective as all participants contributed to the discussions.

The author was sensitive to the fact that the context of each focus group discussion could influence participation in the group discussions. The context being the setting and influencing factors specific to the setting, these can be physical, emotional, cultural, political and and/or academic; and they can be real or perceived. Physical issues may relate to the venue and how appropriate and comfortable it is. The following factors may also have an impact on the context of the focus group discussions:

- Some of the groups were mixed gender and in some African cultures, women are expected to be submissive which could have kept them from openly sharing in the discussion.
- The groups were made up of different professions, including nurses, doctors and social workers; and nurses and social workers may have deferred to the doctors because they may have seen them as superiors.

The author was careful to take these contextual factors into account and to ensure that the facilitator was sensitive to it so that she could ensure that the atmosphere remained neutral, secure and comfortable for the participants. This proved successful as there appeared to be an open atmosphere of sharing at all the focus group discussions.

The focus group discussions lasted approximately an hour each and were video-taped as well as audio-recorded so that they could be transcribed. This duplication of recording was done to ensure accuracy of transcription. An independent facilitator, the HPCA Palliative Care Development Officer in the Western Cape, who has a social work degree and a master's degree in narrative therapy, facilitated them. An independent facilitator was used to ensure that the focus group discussions were facilitated without any potential bias or influence by the author. This also freed the author to take the video and observe and document pertinent observations.

It was decided that two focus group discussions would be done in South Africa and one each in Kenya and Malawi. This meant that four focus group discussions were planned for the three countries. However, two additional focus group discussions were run as it was decided that a pilot focus group discussion should be done and a second focus group discussion was scheduled for Malawi. The pilot was done to ensure that research questions encouraged discussion related to the topic and that documentation that was developed was appropriate and functional for the process. And, an additional focus group discussion was held in Malawi so as to satisfy the requirements of the Malawian ethics committee. (They felt that one discussion group would not be enough to capture the needs across all the regions in Malawi.)

The focus groups were made up as follows:

Province/country	Location for focus group	Number of participants
Pilot (Eastern Cape)	Grahamstown	5
Gauteng	Johannesburg	8
Western Cape	Stellenbosch	13
Malawi 1	Lilongwe	8
Malawi 2	Lilongwe	7
Kenya	Nairobi	8

Fig 3.1 Demographic detail of focus groups

In South Africa, the focus group discussions were held in different regions; the two focus group discussions that were initially planned were held in the Western Cape and Gauteng as it was felt that these two regions would potentially have different needs and the distance between hospices are shorter and so participation would be logistically easier and therefore more likely. The pilot focus group discussion that was included later was done in the Eastern Cape as this was not going to be covered by the other two focus group discussions.

In East Africa, two focus groups were run in Lilongwe and participants from varying areas of Malawi were involved. It was decided to hold the two focus group discussions at the same venue and ask participants to come in from different regions as this would be more cost and time effective. In Kenya, a single focus group discussion was held in Nairobi at Nairobi Hospice and participants attended from various areas around Kenya.

All focus group discussions were preceded by a “meet-and-greet” and an introduction to the researcher and facilitator and the research itself. After this session, consent forms were introduced and explained and participants were allowed to ask questions and were assured that participation was voluntary and that they were welcome to excuse themselves without fear of reprisal. No problems were encountered during this process and all participants were happy to give consent and participate.

The focus groups were run in a semi-structured way: a discussion topic was introduced and the facilitator guided the discussion using a short list of questions as seen in addendum A. The participants were encouraged to participate and talk about their own experience while the facilitator guided the group to stay on topic and discuss the professional development needs and challenges that they were currently experiencing.

Pilot focus group

The Pilot focus group discussion was held in the Eastern Cape as this was an area that had not been selected for the study. Grahamstown was identified as the most central place within the Eastern Cape and most easily accessible for participants.

This pilot served to establish that the *prompt questions* (found in addendum A) for the focus group discussions would encourage the discussion as expected and yield information pertinent to the professional development needs of palliative care programme managers working in hospices.

Prior to the discussion, information regarding the study was circulated to all participating hospices and the author spoke with managers about the research at site visits leading up to the date. The author also took time to explain the research and the process of the focus group discussions with the participants and went through the consenting process with them.

The following valuable pointers for the focus of capacity building and support were raised:

- Leadership and management
 - A need for support for “middle managers”
 - Conflict resolution training
 - Training in professional communication-verbal and written

- Team building
- A number of clinical issues were also raised:
 - Palliative care training for upper level management and admin staff and local doctors
 - Clinical training for social workers
 - Training in cancer related issues
 - External supportive supervision for social workers

The pilot was a good opportunity to get an idea of how discussions would go and allowed the researcher and the focus group facilitator to identify potential problems. For example, the distances that need to be travelled in some areas meant that even though the discussion itself only lasts one hour, travel time needed to be considered and this influenced the number of participants who were able to devote the time to participate in the pilot focus group. The distances in the Western Cape and Gauteng are not as great and hospices are better staffed so it was easier for managers to release staff, thus attendance was better at these focus group discussions. A similar pattern was evident in Malawi and Kenya.

As no changes were made to the focus group discussion process, the data gathered during the pilot focus group discussion was included in the study and has been reported on in the chapters relating to the results and discussion.

Focus group discussions in South Africa

In addition to the pilot focus group discussion two focus group discussions were held in South Africa, one in the Western Cape and one in Gauteng. In the Western Cape, Stellenbosch was chosen as the most convenient location and in Gauteng, Johannesburg was chosen. Both discussions were well attended with 13 participants in Stellenbosch and 8 participants in Johannesburg.

Focus group discussions in Kenya and Malawi

Two focus group discussions were held in Lilongwe on the 4th of June 2012. Only one discussion was originally planned for Malawi, but the Malawian ethics committee requested that we do two so as to get better coverage of data from the country. They felt that one focus group discussion would not be adequate in their country. The two groups consisted of 7 and 8 participants respectively and represented the greater Malawi area with participants coming from all over Malawi.

One focus group discussion was held in Kenya at Nairobi Hospice on the 6th of June 2012. The group in Kenya had 8 participants who also came from different regions in Kenya so as to represent the professional development needs of palliative care programme managers all over the country.

Phase II: Survey of development needs of palliative care manager in South Africa, Kenya and Malawi

Phase II of the data collection process involved the development and administration of a survey to determine the professional development needs of all palliative care programme managers across the three countries.

Researchers propose that there are strong advantages to online surveys, but they acknowledge that there are also weaknesses in the method.⁽⁴⁰⁻⁴²⁾ Reported weaknesses include high initial costs to set up the online survey and potentially lower response rates if the survey is not preceded by an email to inform potential respondents of the forthcoming survey and follow-up reminder emails. Both of these potential weaknesses were taken into account and the respondents were sent the appropriate recommended correspondence regarding the survey. Set up costs were negligible as the NPO was already a member of Survey Monkey, the online survey site used.

Evans and Mathura, have shown that online surveys have a number of major strengths.⁽⁴⁰⁾ These include their potential reach, speed and time saving, technical advances, convenience, ease of data analysis and low administration costs, to mention just a few.⁽⁴⁰⁾ From enquiries were made in respect of the palliative care programme manager's access to email and internet, it was determined that most palliative care programme managers in the different regions had access to email and internet. It was therefore decided that an online survey would be viable and convenient for all involved.

Evans and Mathur's stated benefits of online surveys which were relevant to this study for a number of reasons:

- For this study, the potential reach of the survey was important, because it crossed national borders and targeted respondents in rural areas.
- Administration costs were also a factor as the study was being done in NPO's by and NPO researcher.
- Due to administrative issues that delayed the commencement of the study, time and expedience were valuable.

Assembling the survey

The author analysed the data from the focus group discussions thematically and from the themes that arose out of the focus group discussions, the author developed a short survey which was posted on survey monkey. The author included questions relating to identification, geography and demographics as well as questions relating to the above themes.

Geographic and demographic information was included in the survey, because it was felt that this information would give insight into the needs in specific areas as

well the different categories of hospice. Hospices included in this study varied from well-established and resourced to very new and developing hospices. Even though this study aimed to identify the overall needs across the board, the author believed that the additional information may be useful if further analysis of the needs was required. If the needs varied considerably from one area or category to another for example, the curriculum which was to be informed by this data could be adjusted to service that particular category or region's specific needs.

All the identified themes were included in the survey and respondents were asked to rate how beneficial they felt the identified themes would be for them in their functioning and/or for their organisation from 1 to 5(1 being not beneficial at all and 5 being extremely beneficial.) See Addendum H for an example of the survey or go to: <https://www.surveymonkey.com/s/RSCZ73G>

Distribution of the survey

As the survey was online, there was no paper distribution required, but an informing and prompting process was required. This procedure was as follows:

- An email informing all palliative care development officers about the survey was sent out and they were asked to notify the study sites about the survey.
- The author then sent an email to all regional managers in member hospices of the relevant national associations in each of the participating countries and asked them to ensure that all palliative care programme managers in all of the organisations log on and complete the survey. (In South Africa, this was HPCA while in the other countries this will be done in liaison with KEHPCA (Kenya Hospice Palliative Care Association) and PACAM (Palliative Care Association of Malawi).)
- Where internet connectivity was problematic, a hard copy of the survey was emailed to the sites so that they could complete it and email it back.

Collection of surveys

All completed and returned surveys were analysed so as to add depth to the existing data collected from the focus group discussions.

Data collection and analysis

Data collection and analysis for this study was done for both phases. Phase I of the study was done by means of focus group discussions and the data collected and analysed for this phase was qualitative data. Phase II of the study was done by means of an online survey which yielded quantitative data. The collection and analysis process for both phases will now be presented as well as the storage and dissemination of data.

Data Collection

According to the second edition of *Research in Practice* it is imperative to work with data in context.⁽¹²⁾ It was especially important to keep the context at the forefront of the data collection and analysis processes for this study as the development needs of the palliative care programme managers were meaningless outside of their context of working in hospices in Africa.

Methodological triangulation

Data was collected in different ways from different sources. As the diagram below illustrates, an initial theory was formulated based on informal information gleaned from the CIDA workshops as well as observations made by HPCA field staff and managers working with palliative care programme managers in hospices in South Africa. Based on this initial theory, a series of focus group discussions were carried out after which a survey was sent out to corroborate the focus group discussion data.

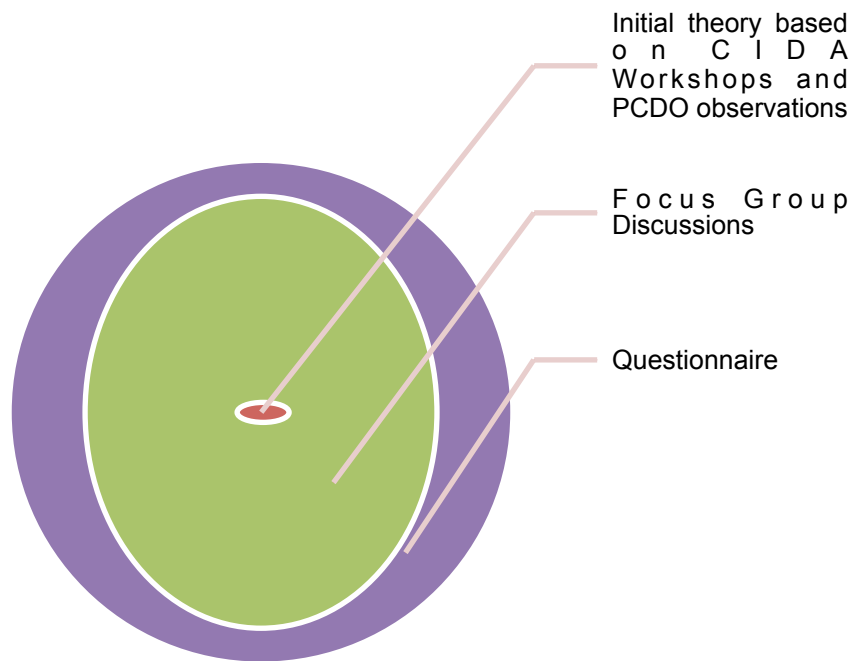


Fig 3.2 Triangulation of data collection

Data collection for this research was done in two phases; qualitative data was collected by means of focus group discussions and quantitative data was collected by means of an on-line survey.

Data collection for Phase I

The data collected for phase one of the studies was done by means of focus group discussions. According to Powell and Single, the focus group is a technique which is used commonly in health sciences research. This technique allows the group the opportunity to discuss the research topic in a structured or semi-structured way, guided by prompt questions.⁽⁴³⁾ (See Addendum A) For this study, the author employed a semi-structured approach, in which the focus group facilitator was given several prompt questions, but was instructed to allow the conversation to flow as naturally as possible.

The palliative care programme managers that were approached were given sufficient information for them to make an informed decision about participation and were asked to sign two consent forms-the first gave consent to be involved in the study and the second gave consent to be video-taped (see addendum F). A consent form was not created for the survey as it was felt that by completing the survey, the participant had given consent.

Preceding the focus groups, the researcher and the facilitator presented extensive information about the nature of the research and the topic for discussion. The participants were then given an opportunity to ask questions before they were asked to sign consent as discussed in the section regarding ethical considerations. The researcher and the facilitator took this opportunity to set everyone at ease and ensure them that the purpose of the focus group discussion was to glean information about the personal experiences of palliative care programme managers and to get an accurate sense of the collective professional development needs of the group.

The above-mentioned information sharing session was very helpful in that allowed the group to understand the focus of the research question and to feel at ease with the facilitator and the group. This meant that the conversations in the focus groups flowed quite naturally and the conversation remained, for the most part, on topic with little prompting from the facilitator.

The data collected from the focus group discussions was recorded and the author then transcribed the recordings verbatim.

Data collection for phase II

In qualitative research methods, the data is filtered through the subjective interpretation of the researcher and in order to reduce bias, the researcher has used two different methods to collect data.⁽⁴⁴⁾ The data collection for phase two was done by means of a survey. This second phase of data collection was done with intention

that it would ensure that the data collected from phase one had been analysed and interpreted correctly.

As discussed in the previous chapter, the survey was developed from the themes that arose from the focus group discussions and included demographic data of respondents. The survey that was developed was put up on survey monkey, a free survey website that can be accessed from anywhere in the world so that palliative care programmes managers working in hospices in Kenya, Malawi and South Africa could log on and give input into the validity of the data that had been collected during the focus group discussions. A graphic presentation of the quantitative data gleaned from the survey is documented and discussed under the findings section of this dissertation.

Data Analysis

There were two types of data that needed analysis. In phase I of the study, the recorded focus group discussions were transcribed and analysed thematically. The data generated by the online survey was analysed by survey monkey, the online website used to do the survey.

Process of data analysis for phase one

The process of data analysis for phase one of the studies involved the following steps: data preparation, reading of the text, analysis of the text, identification of emergent themes.

Data preparation

The focus group discussions generated raw data in the form of audio-recordings, which were transcribed by the researcher. “The benefits of the researcher transcribing is two-fold: it is cost saving and enables the researcher to become immersed in the data while transcribing.” (12)

Reading of text

According to Lapan et al comprehensive and detailed reading of the text forms an integral part of the initial coding process.⁽⁴⁴⁾ Taking this theory into account, the author read the text numerous times and notes were made in the margins relating to professional development needs that were identified by participants of the discussions. The author believed that reading the data in this way would allow all interesting issues to emerge naturally.

Analysis of the transcribed texts

Thematic analysis was done manually using the following analytic process:

All the focus group discussion video data was transcribed by the author using the additional audio-recordings to verify accuracy of transcription. Each participant in the focus group was numbered according to the order in which they participated and the facilitator was indicated by an “F” to distinguish her narrative from that of palliative care programme manager participants.

Thereafter each focus group discussion transcript was read and the author used this careful reading process to construct initial codes that were grounded in the data. ⁽⁴⁴⁾

A list of all the categories was compiled for each group. A similar process was followed for each focus group discussion. The categories were then combined in one list. On this list all categories were listed even if they were repeated. The categories were then put into themes of identical ideas, after which similar or related ideas were grouped into bigger groups or themes.

After extensive reading and analysis of data was done, three main themes emerged and these: professional development, training and palliative care training for non-clinical managers and staff. The second theme; training, had seven sub-themes. This data was used to develop the questionnaire for the on-line survey.

Analysis of data from phase II

Phase two of the study was done by means of an online survey and the data from this phase of the study was analysed by the web survey programme and a graphic report of the data was generated. The findings and further analysis will be discussed in the next chapter.

Validity of data

According to Terre Blanche et al; validity refers broadly to the soundness of the conclusions that are made by the research.⁽¹²⁾ In qualitative research credibility of data is important and credibility, trustworthiness and generalizability were of paramount importance in this study as the findings would be used to develop a curriculum and training material for palliative care programme managers in East Africa, a process that involves significant funding requirements in a resource poor environment.

Two sets of data were collected for this study, namely the qualitative data from phase I and the quantitative data from phase II. The validity of each set of data will be dealt with separately referring to the different types of validity, namely; internal, external, measurement, interpretive and statistical validity.

Phase I: Qualitative data

The qualitative data for phase I was collected by means of focus group discussions and analysed thematically. This data, once analysed was intended to inform the development of a training curriculum and training material and it was very important that the emerging themes be an accurate account of the professional development needs of patient care managers and therefore valid data. The author predicted two areas in which the results could possibly be corrupted: during the focus group discussions and during the analysis process.

The author was concerned that the focus group discussions may generate data that did not exhibit internal validity, because it did not focus on the relevant professional development needs. This would result in the emergence of themes that may not represent priority development needs which may lead to the development of irrelevant training material. The author was therefore very careful to instruct the facilitator to ensure that the focus groups discussions were facilitated correctly. A list of prompt questions was devised and a pilot focus group discussion was facilitated in the Eastern Cape to verify that the prompt questions and facilitation of the focus group discussions would lead to discussions about professional development needs among the group.

The pilot focus group was successful in that it did generate discussion about the professional development needs of palliative care programme managers and that these needs mirrored, to a large extent, the needs that were identified during the CIDA workshops. This gave the author confidence that the research topic was relevant to the target group.

To increase the validity of the findings, the data was triangulated in that data was collected from different sources. Initially, the theory that palliative care programme managers needed training and support in the managerial function was based on information that that was provided by palliative care programme managers at the CIDA workshops previously mentioned. Focus group discussions were held in South Africa, Kenya and Malawi during which participants were asked to discuss their

professional development needs. Based on the focus group discussions, a survey was developed and posted on line for the greater palliative care programme manager population to complete.

The author was also concerned that the proposed training curriculum and material was intended for palliative care programme managers in the greater South and East Africa region so external validity in the form of generalizability was considered. For this reason it was decided that focus group discussions should be conducted in at least two other countries in the region and participants would be invited from different regions within each country. These two countries, Kenya and Malawi, were chosen because, as discussed during the introduction of this paper, the circumstances and resources are relatively diverse. This diversity of the three countries involved was intended to increase the generalizability of the findings so that the intended outcomes could be met for the entire South East Africa region. Representatives who attended the pilot training course gave feedback which indicated that the training would be useful and appropriate in their setting.

During the analysis process, the author was concerned that the themes may incorrectly be prioritised which may lead to emphasis being placed on less needed training topics and more crucial topics being neglected. This concern was kept in awareness during the analysis process and the author managed to ensure that all the identified training needs were included in the themes which were developed. In phase II of the study, participants were requested to rate their need for development in a particular area which also ensured that priority would be given to the correct themes during the development of the curriculum and training material.

Phase II: Quantitative data

The quantitative section of this study was done to assess the interpretative validity of the qualitative data. The collection, collation and analysis of data for this phase of the

study was done by the on-line survey site, Survey Monkey which ensured statistical validity.

Ethical considerations

In designing and conducting this study, the declaration of Helsinki and its stipulations have been taken into account. The HPCA code of was also consulted in the design of the study. The rights of all participants were respected, including issues such as autonomy, beneficence, non-maleficence, justice and confidentiality. Special attention was given to the specific information needs of individual potential participants. This information was given in the form of an information leaflet as seen in addendum B.⁽⁴⁵⁾ The safety and protection of all participants was prioritised and all participants received sufficient information before being asked to sign an informed consent form as seen in addendum C. Participation was entirely voluntary and participants were given the opportunity to opt out of the study at any time without incurring any negative consequences.

The participants involved were all professional healthcare personnel who are legally competent to consent for themselves. Each participant was informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the author, the anticipated benefits and potential risks of the study and the discomfort it may entail, and any other relevant aspects of the study.⁽⁴⁵⁾ The research did not infringe on their right to autonomy in any way and participants did not experience any distress due to participation in the study, but provision was made for access to counseling on the off-chance that a participant experienced distress due to or during the focus group discussion.

Participants were reassured that they would be treated fairly and that they had the right to refuse to participate in the study or to withdraw consent to participate at any time without reprisal.⁽⁴⁵⁾ The author's motive was to gather information that could lead to improving the work environment for palliative care programme managers and increase their productivity and sense of job satisfaction.

Ethics approval was obtained from the relevant authorities in Kenya and Malawi concurrently with the application in South Africa. Ethical approval was obtained from University of Cape Town's Human Research Ethics Committee in August 2010. (Please see Addendum G for copies of the approval letters.) Following this approval it was submitted to the HPCA research ethics committee and it was sent to liaison personnel in Kenya and Malawi: Dr Zippy Ali and Lameck Thambo respectively, who facilitated the processing of the ethical approval in their respective countries.

The proposal was submitted to the respective ethics committees in Kenya and Malawi who then requested additional information and changes, which were duly made and submitted. All ethical approvals were obtained by end March 2012. Only after all the relevant ethics approvals were received, did the study commence.

All the data from the focus group discussions was recorded and the data has been stored on a flash stick and locked in a secure cabinet. This data has been kept with the rest of the data and documentation generated for this study and will be preserved for five years.

Conclusion

Purposive sampling was done for phase one of the study, while the entire population of palliative care programme managers was targeted for phase two, which took the form of an online survey.

The data collection for this study was done in two phases. This was done in order to strengthen the validity of the data and ensure its usefulness for the intended outcomes of this study. Phase one data was collected through focus group discussions. Phase two data was collected by means of an online survey. The data will be presented and discussed under the findings and discussion chapters.

Analysis of the data was done by means of a thematic analysis in phase one and in phase two, the quantitative data was presented graphically. Findings from the analysed data was used to develop a training curriculum, training material and a job profile for palliative care programme managers working in Kenya, Malawi and South Africa. Extensive measures were employed to ensure the validity of the data.

Chapter 4

Findings

Introduction

The findings for phase I and phase II of the study will be presented separately and discussed in detail in the next chapter. The findings of phase I will be presented in narrative form and the findings of phase II will be presented graphically.

Phase I findings

Phase I took the form of focus group discussions that were transcribed and analysed thematically so, the first phase of this research yielded data in the form of themes. The themes will now be presented and supported using quotations from the focus group discussions. These quotations will be written in italics and the identification in brackets thereafter using the following format:

Focus group discussions will be identified and the participant number for that particular focus group discussion will follow. The focus group discussions will be identified by an abbreviation of their location as follows: Western Cape (WC), Eastern Cape (EC), Gauteng (G), Malawi 1 (M1), Malawi 2 (M2) and Kenya (K). Participant one from the Eastern Cape discussion group would therefore be identified as EC: 1 and participant 5 from the second Malawi discussion group would be M2: 5 and so forth.

The three main themes and their sub-themes

Three main themes emerged: professional development, training and palliative care training for non-clinical managers. These three main themes and their sub-themes are shown in the following table and then discussed in detail below.

The three main themes with their sub-themes		
Palliative Care Training	Professional Development	Training needs
<ul style="list-style-type: none">• For :<ul style="list-style-type: none">▪ Doctors▪ Non-clinical managers and staff▪ Networking partners	<ul style="list-style-type: none">• Coaching, mentorship and supervision• Forums	<ul style="list-style-type: none">• Professional Development• Human Resource Management• Resource Management• Team dynamics• Stress Management• Monitoring and Evaluation• Advocacy

Fig 4.1 The three main themes and their sub-themes

Palliative care training

Firstly, it was felt that many of the doctors working in palliative care, either directly or indirectly were in need of palliative care training as voiced by a participant in the Eastern Cape who said:

I don't think doctors know palliative care anymore. (EC: 5)

This participant felt that the doctor's lack of palliative care training hindered the hospice staff's ability to work optimally with the doctors to manage patients and impacted on the quality of palliative care that was given which she illustrated by saying;

And sometimes you find that when you reach the patient, the patient doesn't even know the diagnosis. (EC: 5)

In Malawi the greater concern was the lack of availability of palliative care training for palliative care practitioners. The participants shared that palliative care is a new concept in Malawi which is not yet adequately supported by their ministry of health. They went on to say that certified training is not yet available in Malawi and people need to travel out of the country in order to get trained and that this is very difficult as Malawi is a poor country with minimal resources. They were also concerned that the lack of certification for training makes it an undesirable field to move into.

One participant from the Eastern Cape felt that the focus of palliative care training in South Africa needed to be reviewed. She felt that as a whole palliative care training in South Africa put too much focus on HIV/AIDS and TB and not enough focus on cancer and other life-limiting illnesses:

I think there is too much focus on HIV and AIDS and there is nothing on cancer. I think we need a huge amount of work in cancer, so that we actually attract cancer patients back to the hospice. I think palliative care has become focused on only HIV and TB which has become medical and we are forgetting end of life care. (EC: 1)

Another concern that was raised was the lack of training in palliative care for non-clinical managers and staff when a participant said;

Management themselves, should have some knowledge of palliative care. (EC: 4)

It was felt that a lack of palliative care training for these managers and staff impacted on the quality of support that was given to patient care staff and it was felt that this lack of knowledge also affected managers ability to manage resources within the hospice optimally and created conflict among the staff and management. When the above mentioned participant was asked how she thought that the non-clinical managers and staff's understanding of palliative care would affect her patient care team, she replied;

In understanding us, where we're coming from in palliative care. In understanding us as a whole as a team and for making decisions first of all and the way forward and then this conflict will be eliminated or you know, will become less. Ja, then we have one voice. (EC: 4)

This was illustrated by a participant who shared an example from her organisation;

Yesterday, we got ambubags from the private hospital and then we had to explain in the management meeting why we couldn't use ambubags on the patients and the fundraiser couldn't understand it. She found it quite offensive. (EC: 4)

This concern was shared by participants in Malawi who shared their experiences of administrators who prioritise meetings over patient care. Another Malawian participant asserted that;

Palliative care managers need to be trained, because it is not the same as general care, so there is that need whereby we could come up with palliative care management itself. (M2: 6)

This participant was supported by another who said;

You know, when you are managing patients in palliative care, you know there are special conditions. (M2: 4)

From this discussion, it would appear that these special conditions need to be taken into account in the process of managing palliative care programmes, but in the Western cape discussion, a participant was adamant that;

Palliative is palliative and management is management. (WC: 2)

This participant went on to say that she thought that;

Management skills are kind of, it doesn't matter what you're managing, it's the ability to manage. (WC: 2)

Her thoughts were however contested by other members of the group who felt that even if you don't look at palliative care management as having particular needs, you do need to acknowledge the particular needs related to clinical management and the medico-legal risks involved.

The Eastern Cape group felt that networking partners should also be given palliative care training as it was felt that this would improve those working relationships. As voiced by one participant who said;

So that we can be on the same level, because we are all working toward the same goal. (EC: 4)

Training in palliative care for doctors and non-clinical staff was raised as a need by palliative care programme managers across the groups, because they felt that this training for doctors and non-clinical staff would reduce conflict and improve the quality of the service given. In the East Africa groups, palliative care training for all staff was raised as it would seem that this training is not readily available to them even though there has been a strong drive to bring palliative care training to Africa to help deal with HIV/AIDS crisis.

Professional Development

Alongside the need for training, palliative care programme managers identified a need for mentoring, coaching and supervision as well as a platform to share their concerns and get peer support. The term professional development was used to encapsulate this need. This theme therefore, includes topics such as coaching and mentoring as well as on-going forums and/or discussion groups in the different regions for palliative care programme managers to come together and discuss the management function of their job and any issues that come up related to management. Readers will note that the professional development theme also appears under the training section. This is not duplication, palliative care programme managers voiced the need for this kind of support for themselves and they voiced a desire to learn how to provide this kind of support for their team.

The groups indicated that they get very little support in their management function from higher management levels or from external sources. As one participant from the Eastern Cape group said;

I don't get that support and supervision that I really need (EC: 2)

A participant from Kenya said;

We haven't reached a stage where we have mentors, really, I don't know of any support systems. (K: 6) In Kenya, the group added that there are many resources for knowledge and experience among the hospices, but they need someone to facilitate the sharing of those resources. (K: 6)

The Malawian group expressed the need for consultation with senior managers which involves target or goal setting and support to achieve these set goals, much like the process involved in coaching. (M2: 6) The lack of support for managers to participate in continuing development such as on-going training, which is evident because senior managers do not provide funding for on-going training opportunities and/or won't release them from work to go to the afore mentioned training opportunities was also discussed. (M1: 7&8)

Support in the form of forums or discussion groups was discussed and in Gauteng, one of the group members said;

I think for the managers, it can be better for them if sometimes they can go together and share some information. (G: 4)

Another participant from the Gauteng group shared that she felt isolated and in need of support in managing care givers. (G: 1)

All the groups referred to a need for professional development and support and in most cases, the way they describe how they imagine this professional development would look, is comparable. They describe having the opportunity to have one-to – one sessions with their manager or an external person and they describe forums or peer discussion groups where could have the opportunity to discuss difficulties and best practices.

Training needs

The third theme, training needs, was a collective theme in that there were a number of training topics identified by the palliative care programme managers which they felt would benefit them and assist them to function more optimally as palliative care programme managers. In fact, there were seven main training themes that emerged which included all the training topics identified by palliative care programme managers. The training themes identified were: professional development, human resources management, resource management, stress management, team dynamics, advocacy and monitoring and evaluation. These training topics will now be discussed individually in more detail.

Professional development

As well as their own need for professional development which, as mentioned above, included coaching and mentorship of staff, capacity building, staff empowerment, motivation of staff, accountability of staff, person-centred management, supervision and holistic management; the palliative care programme managers across the groups expressed the need to acquire the skills to assist their staff with this kind of professional development.

In Gauteng, a participant expressed that she would benefit from training in how to develop her caregivers. (G1) She felt that their development required a different approach due to their lack of training and experience and sometimes a lack of accountability and ethics; and that she was having real difficulty reaching them on this level. The issue of accountability was discussed in several other groups as well.

The Gauteng group also verbalised that they try to employ a person-centred approach to managing and they endeavour to empower staff, but they have not had training in how to do this effectively. The Eastern Cape group added that;

Educating caregivers is an on-going thing and that standardised training material would be helpful. (EC: 5)

One participant was concerned that all hospices are spending time developing training material on the same training topics for their staff. She felt that a standardised training package should be developed so that every organisation wasn't spending valuable time to create similar or repetitive training material. (EC: 1)

In the Western Cape, managers discussed the potential of using the performance appraisal system to identify potential in staff members as well as potential skills development areas that could be addressed. One participant shared;

We take those needs identified at the performance appraisal and put them in a skills development plan where there is one for each staff member. (WC: 9)

Another participant queried how this would happen to which she answered;

It's a challenge, but you keep reviewing that and, for example, we have supervision with staff and you could use that as a platform to address it. (WC: 4)

The Western Cape group also expressed a need for a standardised approach across organisations for measuring skills and training needs which could be circulated and shared.

In Kenya, they too asserted that they use an appraisal system as a basis for the professional development and support of their staff as verbalised by a participant who said;

We have an appraisal system so that at the end of the year we can discuss with the staff so that they know where they have done well, where they are finding challenges and if there are any courses that they can do to improve. (K: 3)

In Malawi the group felt that it was important for managers to motivate staff;

Because when people are motivated they are going to render their service from the heart. (M2: 5)

The need for motivation was supported by another participant who talked about the fact that;

The work in the hospice environment is stressful and not always desirable and that palliative care programme managers need to be able to keep their staff motivated in order to ensure quality care as well maintain staff retention within the programme. (M2: 6)

This group went on to talk about the importance of feedback and communication in supervision, as one participant put it;

So continuing the performance feedback no matter what it is, is very guiding. (M2:6)

They rounded the conversation about professional development off by saying;

The need for mentorship and supervision. (M2: 5)

This mentorship and supervision was identified as essential to effective skills transfer. So this group also, identified the need for palliative care programme managers to be able to provide or facilitate mentorship and supervision for their staff.

In general, the groups all mentioned staff capacitation, or professional development as an important part of their function and a skill that they would value being more proficient in. This need for professional development which includes concepts such as mentorship, coaching support, supervision, motivation, staff empowerment and capacity building; has therefore been found to be a need that is cross-cutting through all levels of employees in the hospice environment.

Human Resource Management

In four of the six groups, human resource management functions came up as a training topic. Participants mentioned human resources itself as well as personnel management and other terms which fit under the theme human resource management such as: legislation, disciplinary codes and procedures, performance management, interviewing applicants, staff planning, staff retention and monitoring of staff.

One issue that came up in a number of the groups and in the CIDA workshops which prompted the inception of this research was how to monitor and manage lay caregivers. A participant in Gauteng put it like this;

We trust that they will wake up in the morning and go and do the home visits (G: 6)

She went on to say;

I have seen that as a manager, I need guidance or help when the person is not performing well. You know performance management. (G: 6)

In the Western Cape a participant said;

It's easier to manage professional people, because they are bound by a code of ethics. (WC: 11)

The Western Cape group went on to discuss the need to develop relationships and build up loyalty among caregivers as they found that they have a high turnover of caregivers who appear to use hospice and the training they get in hospices to better themselves and make themselves more marketable for more lucrative positions elsewhere. One participant said;

With a lot of care-workers there's a fast turnover, people coming in and exploiting the system or trying to improve their own lives and finding that it impinges and doesn't improve, so, there are a whole lot of management issues there. (WC: 2)

The discussion in the Western Cape also dealt with many human resource issues. They verbalised that they felt ill-equipped to deal with disciplinary procedures as well as staff planning, staff retention, interviewing staff at higher levels and performance management. In discussing her insecurity in dealing with matters related to labour legislation, one participant said;

It's about learning how to avoid ending up at the CCMA. (WC: 4)

This participant added that;

There's a huge amount of HR stuff that one flounders into and it is a mine field. The same participant added; it's just because we don't have a strong foundation in this kind of thing. (WC: 4)

In Malawi the concern around human resource management issues continued when a participant responded to being asked about what he would like to be included in management training for palliative care programme managers in the following way;

I think it would be nice if they added HR management skill. (M1: 5)

He went on to add;

We would like a concept of management, how to manage other staff. (M1: 5)

A third member of the Malawi group added;

I discovered that I had gaps in terms of managing my people. (M2: 1)

This group also discussed the need for further training in performance management, staff retention, and recruitment and orientation of staff.

In Kenya, one participant admitted that her insecurity lay in producing human resources documentation; personnel files, job profiles, HR manuals, orientation packages, performance appraisals, etc. (K: 5) The group concurred that they too shared her insecurities and added that they also felt that they would benefit from training that included all issues related to human resources.

A common finding across the groups was the need for training in human resource functions. HR functions identified by the groups included: performance management, staff planning, disciplinary procedures, legislation and the administration that accompanies all human resource management activities.

Resource Management

This theme included all fundraising activities, resource mobilisation, proposal writing, report writing, networking and the prioritising of resources and projects.

A participant in Kenya said;

We know that hospices are a charity and you have to look for the resources for yourself, proposal writing for me was a priority. I had to go out of my way just to look

for opportunities so that I know how to write proposals in order to generate income for the hospice. (K: 3)

Another participant said;

I think that applies to all of us (K: 2) and the group concurred.

In addition to proposal writing and fundraising, the groups discussed the need for better skills with the management of resources; monitoring and evaluation as well as report writing for the board and for funders. Report writing and written and verbal communication were also mentioned across the groups, an issue that filters into a number of the themes including professional development, human resources and team dynamics. Palliative care programme managers also verbalised that they believed that they would benefit from increased skills to manage existing material and human resources optimally;

You have to network with all these people and if you have been lucky, you get funding from some of these international organisations, they expect you to manage their money in a certain manner, to give certain reports, you know, in a specific way. (K: 3)

This theme which included discussions relating to: all fundraising activities, resource mobilisation, proposal writing, report writing, networking and the prioritising of resources and projects was more common to the East African discussion groups.

Team Dynamics

This theme refers to all the tasks related to managing teams and the relationship dynamics involved in team functioning including: communication, conflict management, and group cohesion and change management.

In the Eastern Cape group discussion, a participant shared that she felt that there is a gap regarding managing the staff and the conflict management that goes alongside

managing a team. (EC: 2) Another palliative care programme manager in the Eastern Cape group added that she had noticed that all hospices seem to have a division between the psychosocial and clinical teams. She went on to say;

We're meant to be providing holistic care, we're meant to be working together, but for some reason, I think every hospice has a problem. (EC: 1)

In paraphrasing a conversation during the Western Cape group the facilitator said;

So, the principle in interdisciplinary in how we approach our patients could be paralleled with how we provide support and supervision to the staff. (F)

In Malawi, the diversity of the team was discussed alongside the fact that special skills may be required to manage that diversity. A Kenyan participant added;

Staff have their own issues which you can afford to ignore in a main hospital, but in the hospice, I find to work as a team, you have to confront all those delicate issues so that is something. (K: 2)

Participant 4 responded by saying;

It's very true, because management brings up very pertinent team dynamics, because there are stress issues that come in that affect the work so, to be able to manage their stress so that work can continue is a real challenge. (K: 4)

Another participant talked about how she needed to be able to identify her needs and be able to ask the team for help, which links with the theme above that relates to resource management, because the team and its members are resources to the palliative care programme. (K: 3)

The groups brought up communication as a skill required for effectively managing a team. Specifically, one participant spoke about the need for effective referrals within the team which cannot happen if the palliative care programme manager and his/her team members do not have good communication skills. When talking about training in communication, a participant from Malawi said:

The communication should be on communication to patients, communication to fellow staff and communication with the management team. (M2: 5)

A participant from the Eastern Cape group also suggested that training in communication would be helpful by saying;

So, ya, maybe some sort of training in communication. (EC: 3)

Another participant from the Eastern Cape group talked about the need for good communication skills in information sharing among team members. (EC: 4)

Along with the need for communication skills, the groups discussed the need for good interpersonal skills as well. They felt that good interpersonal skills are fundamental to a healthy and effective interdisciplinary team. One person said;

The interpersonal relationships, I have difficulty with that. (G: 1)

Connected with interpersonal relationships; conflict management was also raised as a discussion point. In Malawi, it was said that;

It is important as a manager to have conflict management skills. (M2: 6)

Components of the team dynamics theme were discussed across the groups and it was found that managing teams is a skill that the palliative care programme managers require.

Stress Management

The theme Stress Management includes not only stress management, but time management as well. This theme refers to the ability of managers to assist their staff in managing the demands that are placed on them so to prevent burnout.

A palliative care programme manager from the Western Cape made the following comment;

Another to manage, I find, is burnout for all staff and especially for carers, because death and dying are so close to them. I mean our carers deal with it a lot and to manage burnout. There's not enough support. (WC: 3)

Another palliative care programme manager from the Western Cape added that they are very mindful of the needs of caregivers and that they have developed a programme to support caregivers, but that no one has the time to run with the programme, which brings up another issue that impacts the stress levels in the team: time management. Time management and the fact that the palliative care programme managers find that they just don't have time to get all aspects of the job done. One participant spoke specifically about not having the time to implement their staff resilience programme;

We are very mindful of the need for the caregiver and for all the staff, but it's actually to get someone to run with the programme, because I think most of us are a bit sort of burning the candle at both ends, across the whole system. (WC: 8)

Another participant from the same group said; *all of this stuff basically boils down to the same; we don't have enough time.* In this group it was also said that; *time is the biggest issue. (WC: 6)*

In the Kenyan group, the fact that most palliative care programme manager have to multi-task and usually have more than one function which adds to the stress experienced by palliative care programme managers was discussed and one member of the group put it this way;

You will find because of the limited resources, a nurse may have to combine a bit of nursing and something else, and for a manager, it is a challenge, because people feel maybe they are overworked, they feel maybe they are not skilled enough. (K: 3)

The Western Cape group identified the need to be present with the staff and it was felt that a holistic or person-centred management style would help managers to identify and prevent burnout more readily;

To be present with them. Whether you are present physically or mindfully with them, it does make a difference to their production and also identifying burnout. (WC: 10)

The problem of stress and burnout among hospice staff was discussed at length in the groups and it was found that it is a common problem across the groups and across the countries.

Advocacy

This theme includes the concepts such as marketing, awareness and networking as the discussions seemed to link these concepts. Advocacy on different levels was discussed. The groups discussed the need to advocate for their staff, for their organisations and for palliative care.

In Kenya and Malawi, the need to be able to effectively advocate for policy change, funding and training was voiced repetitively. One participant said;

We need support from the ministry of health. (M1: 1)

A colleague in the group when talking about the availability of training said;

We fail, because there is little support and they take palliative care as a programme of little importance. (M1: 8)

In the second Malawi discussion, they discussed the need to advocate for chemotherapy as to date chemotherapy is unavailable to their patients. One participant touched on two different aspects of advocacy when he said;

Advocating the need for palliative care for patients. For example, in this country, it does not have chemotherapy, it doesn't have radiotherapy, but people don't know that they can benefit from palliative care. (M2: 5)

In this statement he highlighted the need to advocate for policy change regarding available medical resources for cancer patients as well as the need to create community awareness regarding the benefits of palliative care.

A Kenyan participant also raised the need to create awareness and advocate for palliative care;

What comes to my mind is awareness about palliative care, because I do know that there are still healthcare professionals who don't know about palliative care. (K: 7)

With regard to advocacy, it was found that this is a skill which is required by palliative care programme managers to perform a number of their duties. They advocate for the patients and their staff, they advocate for funding and policy changes and they advocate for palliative care.

Monitoring and evaluation

Monitoring and evaluation was identified as a training need in two ways. Palliative care programme managers felt they needed training in Monitoring and evaluation of data and of staff.

In relation to the monitoring of their staff, palliative care programme manager's verbalised that they find that it is very difficult to keep track of staff members who are out in the field. A palliative care programme manager in the Gauteng group said that the fact that caregivers leave from their homes to do home visits and go back home without reporting in to the office most days (this is due to the traveling distances) makes it very difficult to be sure that they are putting in the number hours that they are supposed to. (G: 3)

In the Western Cape, a participant echoed this problem by saying;

I'd just like to say something about the carers that work in their communities, so they work from home. To try to manage that is also a huge problem, because we don't know that they are going to work at 8 o'clock and finishing at 1 o'clock or 3 o'clock or whatever their contract states. The control over that is also a huge problem and I'm not sure how one can overcome that problem.

According to the discussions, palliative care programme managers need to be proficient in monitoring and evaluation functions on two levels. Monitoring and evaluation of their staff and of data.

In summation, three main themes emerged: professional development, palliative care training for non-clinical managers and training in management functions for palliative care programme managers. This last theme had seven sub-themes and the findings for phase one of the study indicate that there are strong training needs in various topics related to management for palliative care programme managers. The findings also suggest that these needs are cross-cutting and that the groups in all the regions of the countries included in the study identified similar or comparable training needs related to the role of palliative care programme manager.

Phase II findings

In this section the results of the online survey will be presented graphically and discussed further in chapter 5. The findings for this phase of the study were based on the results of the on-line survey and will be presented in the order of the questions that were asked.

The survey was divided into three sections:

Section 1: Demographic details

Section 2: Questions relating to profession and previous training

Section 3: Questions based on the themes which emerged from the phase 1 focus group discussion findings.

Section one

Question one and two of the survey required the participant to give their name and the name of the organisation that they work for. Both these questions were optional and of the fifty one respondents who completed the on-line survey, one person skipped question one and two people skipped question two.

Question three asked respondents to indicate the country in which they worked and of the fifty one who completed the survey, two skipped this question. Figure 4.1 represents the results of the question relating to the representation of the three countries. It was felt that it was important to know that all three countries were represented. According to figure 4.1, the majority of the respondents were South African with 37 of the 49 who answered the question being from South Africa and 9 and 3 from Kenya and Malawi respectively. This was expected due to a number of factors. Firstly, there are more hospices in South Africa than in either of the other two countries. Secondly, HPCA is more developed as an organisation with more regional representatives to encourage participation. Thirdly, access to email and internet in Malawi and Kenya is not as good as it is in South Africa. Overall, it was felt that the representation was acceptable.

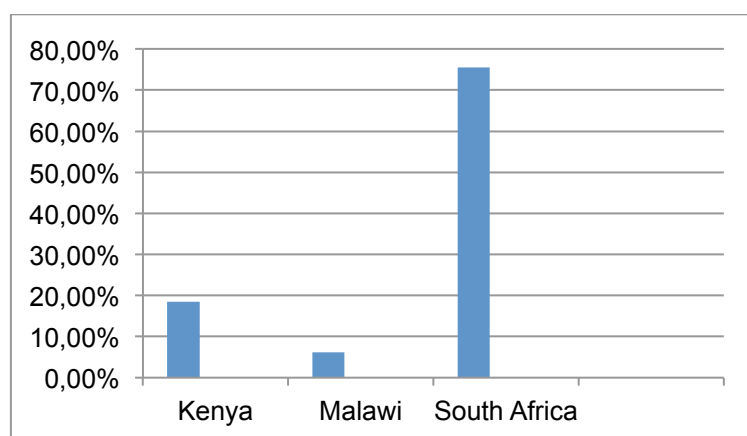


Fig 4.2 .Representation from the three countries

Question four required respondents from outside of South Africa to confirm how long their organisation had been established. Twelve respondents, who were not South African, answered this question and answers varied from 1 year to 14 years.

Question five, the respondents were asked to identify whether their organisation worked predominantly in an urban setting or if their organisation was more rurally situated. This question was asked to identify potential support networks as it is recognised that those organisations that work in a more rural setting have access to fewer resources and less support.

Figure 4.2 shows that more palliative care programme managers work in a rural environment as opposed to an urban environment. It is however recognised that the option to answer *both* was not given and in many instances, hospices may cover the urban setting and the surrounding rural area which accounts for the fact that some hospices checked both urban and rural.

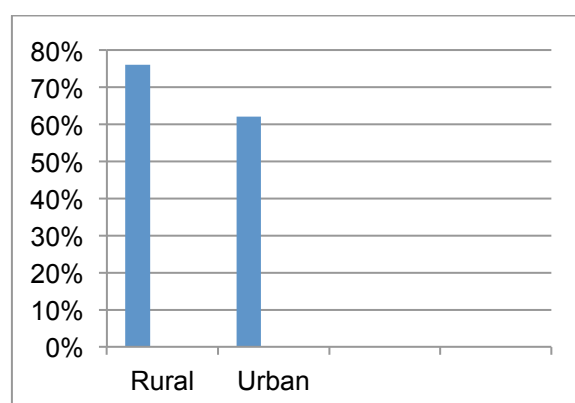


Fig 4.3 Rural Organisations vs. Urban Organisations

In South Africa, hospices are rated according to a star-rating system depending on their level of development. One star hospices are newly developing hospices and five star hospices have been audited by an external auditor according to the HPCA standards and have achieved at least 80% for all their service elements. The Kenyan and Malawian organisations have not yet introduced standards or categories for their

organisations so they were asked to identify themselves in the last column: site outside of South Africa.

Question six related to the category of the hospice as per the star ratings applied by HPCA and those working in organisations outside of South Africa were identified column six of figure 4.3 which indicates that the majority of palliative care programme managers who answered the survey are from five star organisations. Again this is not surprising as these organisations have more contact with HPCA and are more resourced and would have the staff and the time to answer the survey.

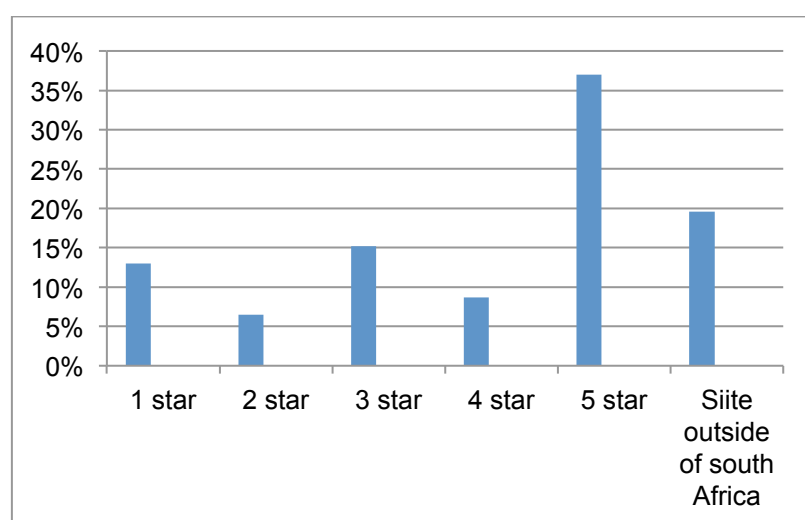


Fig 4.4 Category of Hospice

Question seven inquired about the respondents' profession. Figure 4.4 relates to the profession of the palliative care programme manager. Palliative care programme managers come from a variety of professions, predominantly nursing, medicine and social work. Specifically of the 50 who answered this question; 2 were medical doctors, 26 were professional nurses, 10 were social workers and 13 fell into the category *other*. The option of other was provided for palliative care programme managers to include professions that did not fit into the three listed categories. It was found that palliative care programme managers also include people from professions such as sociology, physiotherapy and theology. There were also a few enrolled

nurses, clinical officers and public health officers who are performing the function of palliative care programme manager.

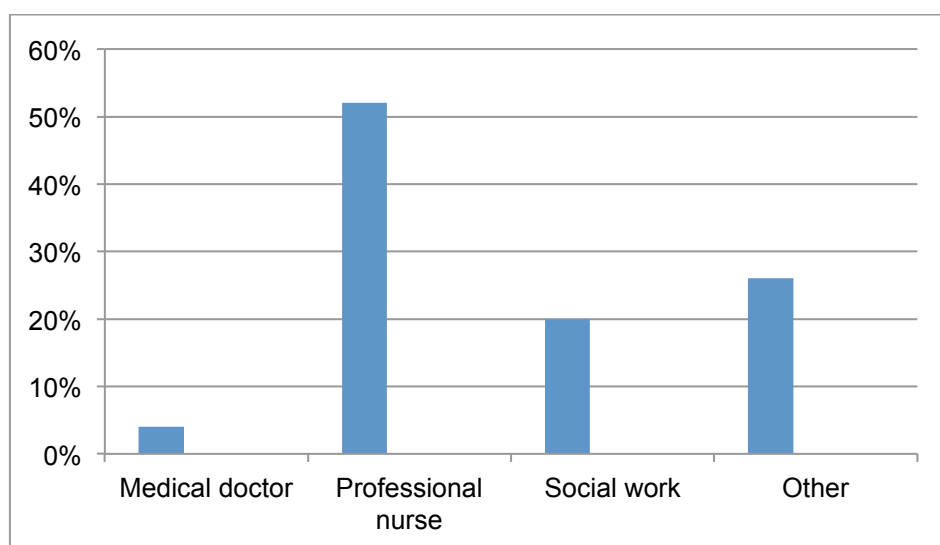


Fig 4.5 Profession of palliative care programme manager

Question eight asked respondents to indicate the role that they play with regard to management. These findings helped to establish the level of management of the respondent. Forty five respondents answered this question and answers included roles such as: nursing services manager, patient care coordinator, managing director, unit manager, clinical manager, community home based care coordinator, caregiver manager, counselling manager, psychosocial manager and palliative care manager.

Section two

The next section of the survey, question nine and ten, asked respondents about their management training. The two figures below show the number of palliative care programme managers who have had management training and the type of training. Figure 4.5 shows that just over half the palliative care programme managers have had some management training. Figure 4.7 illustrates the variety of training.

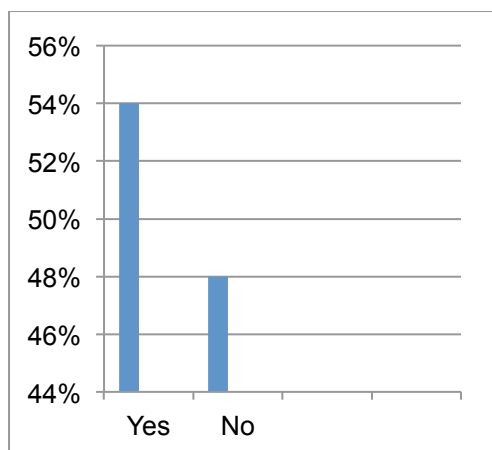


Fig 4.6 Previous management training

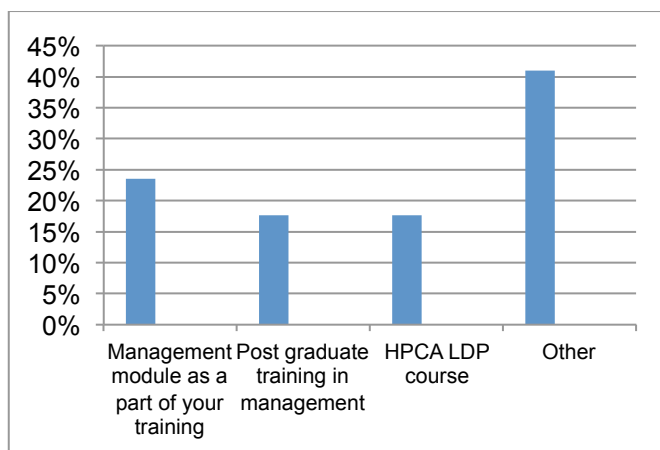


Fig 4.7 Type of training

Types of training include management modules as a part of basic professional training, post graduate training in management, and some of the palliative care programme managers in South Africa have been a part of HPCA's Leadership Development Programme. Some palliative care programme managers also indicated that they had had other training or experience which was not covered in the categories mentioned. Examples of training listed under other include: supervisory skills course, UK general practice training to be a principle/employer and informal management courses.

Section three

The next section of the survey related to the themes that emerged from the focus group discussions. The respondents were asked to rate how much they felt they and/or their organisation would benefit from professional development, palliative care training for non-clinical managers and training in the seven topics that emerged from the focus group discussions: professional development, human resource management, team dynamics, stress management, resource management, advocacy and monitoring and evaluation. The ratings were as follows: 1 for *not at all* and 5 for *yes definitely*.

The perceived need for professional development for palliative care programme managers is illustrated in figure 4.8. This relates specifically to the palliative care programme managers' perceived a need for a mentorship programme that includes coaching and supervision from senior management or external mentors as well as peer support in the form of forums or discussion groups.

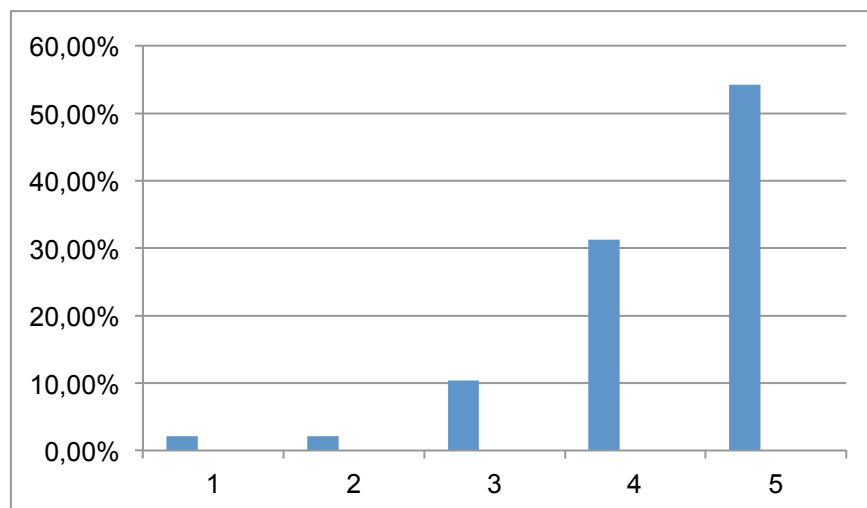


Fig 4.8 Palliative care programme manager rating for the need for a mentorship programme

As noted in the focus group discussions, it is evident from the above graph that palliative care programme managers felt that they would benefit greatly from an on-going mentorship programme.

In question twelve, the palliative care programme managers were asked if they felt that their organisation would benefit if more of their non-clinical managers and staff had some kind of palliative care training as this had been discussed in the focus group discussion and palliative care programme managers felt that conflict often occurred, because non-clinical managers and staff did not understand the nature of the work.

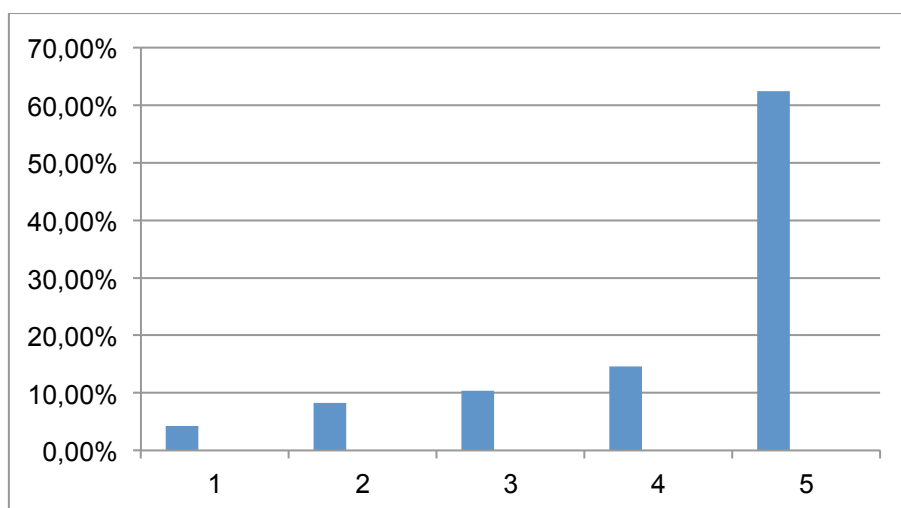


Fig. 4.9 Palliative care training for non-clinical managers and staff

The responses in figure 4.8 show that the greater population of palliative care programme managers agree with the data from the focus group discussions.

Questions thirteen to twenty of the survey, related specifically to the training needs that had been identified in the focus group discussions. Again, the respondents were asked to rate their need as they were in the above questions.

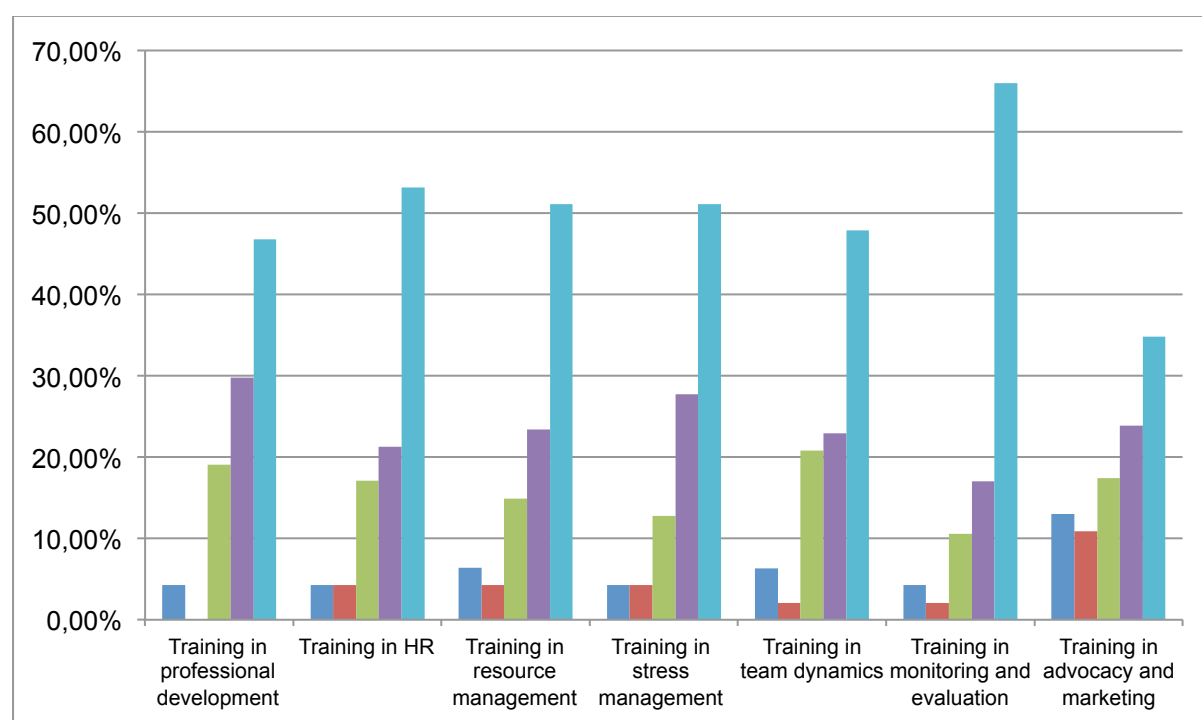


Fig 4.10 Training needs

The responses are recorded from 1-5 starting from left to right. The first bar in each set represents those palliative care programme managers that rated their need at 1 moving rightwards, the ratings increase in denominations of 1 up to 5. In other words, the column farthest to the right represents those respondents who marked their need for the respective training at 5 and the ones in between represent 2, 3 and 4 respectively.

In all the questions relating to training the majority of respondents indicated that they would greatly benefit from the training. It was only in the question relating to advocacy that the responses were fairly evenly spread across 1-5. And if one is to compare these responses to the data from the focus group discussions one can see that although advocacy came up briefly in most of the group discussions, it was in the East African countries that it was given the most emphasis and considering that a larger percentage of the respondents of the survey were from South Africa, this result is understandable.

In order to ensure that no training topics were missed or left out, respondents were given the opportunity to add anything that they felt had not been covered, which they would like to have covered in any subsequent training. The following topics were mentioned: palliative care training for hospice board members, financial management, quality management, strategic planning and logistics management. In addition to these, a number of suggestions were made that had in fact been included in the survey, so perhaps the survey was not as clear to respondents as the author believed. It is also pertinent to note that many of the respondents do not have English as a first language and this could have contributed to the misunderstanding of the questions or the terms. For example, one respondent asked for training in *skills in community awareness* which was indeed covered in the question related to advocacy and marketing. Another asked for training in *time management* which was covered under the question relating to stress management. Other topics that were requested in the last question included: *logistics management*, *supervision training*, *data management and securing funding*. All of these topics were actually covered under the questions that were asked relating to training needs. One respondent

asked for oncology training for doctors which is recognised as a legitimate need, but is not prioritised by this study which focuses on the management needs rather than clinical needs of palliative care programme managers.

Conclusion

The findings that have been presented reveal that, as indicated by palliative care programme managers who attended the CIDA workshops, palliative care programme managers do have professional development needs related to their managerial function and that they require training and on-going support and mentorship

Chapter five

Discussion

Introduction

In evaluating the professional development needs of palliative care programme managers, this study considered an initial hypothesis which was made based on the CIDA regional workshops done by HPCA and set out to question this hypothesis. The CIDA workshops had highlighted that palliative care programme managers lacked the management skills to perform their functions in the new context in which their role was managerial in addition to hands on care.

Firstly, this two phase study was designed to evaluate if the palliative care programme managers felt that they lacked the skills mentioned above. Secondly it questioned the palliative care programme manager's exposure to pre-service and in-service management training. Thirdly, it sought to establish a collective, subjective perspective of the elements required to provide supervision of community caregivers and effectively manage a palliative care programme in the context of HIV/AIDS in South East Africa. Fourthly, it assessed the resources with regard to support and mentorship of the palliative care programme managers.

The findings of phase II confirmed that the focus group discussions in phase I identified the predominant training needs of palliative care programme managers in South and East Africa, but it would be prudent to remember that, there is a desperate need for training in palliative care and healthcare in Africa, especially in the two Eastern African countries, where the resources and availability of training is severely restricted. Palliative care programme managers may be eager for any and all training which could mean that the survey may not have been answered as objectively as the author may have liked, but at the time that this dissertation was being completed, a draft curriculum and training material had been developed and piloted and the feedback from that pilot training course revealed that the findings of

this evaluation and the subsequently developed curriculum and training material did meet the professional development needs of palliative care programme managers working in hospices in Kenya, Malawi and south Africa.

Testing the CIDA hypothesis

It had been assumed, based on the afore-mentioned CIDA workshops that palliative care programme managers working in the hospice context were experiencing a significant shift in their role. This assumption was supported by the literature review which found that the role of health care professionals is evolving to include more and more management functions.^(6, 10, 19-22)

During the focus group discussions, palliative care programme managers were asked to discuss their need for professional development and management skills training. The data from these discussions, suggest that palliative care programme managers do feel that they lack the skills needed to perform their ever evolving function. This was supported by the survey in which palliative care programme managers rated their need for training in management topics favourably.

This data supports the hypothesis which was developed based on information from the CIDA workshops and it corroborates the need for this study based on the experiences of healthcare professionals across Africa. The data suggests a need for further study into the specific development needs of healthcare professionals working in NPO's in the wider HIV/AIDS context in Africa.

Exposure to pre-service and in-service training

The focus group discussions focused predominantly on the current professional development needs of the palliative care programme managers and their exposure to previous management training was only discussed briefly in a few of the groups.

This was identified as a limitation and it was addressed in the survey in which the respondents were asked to indicate their previous exposure to management training.

Based on the brief discussions and the survey, it was found that most palliative care programme managers had had some basic management training as a part of their professional qualification. This training however, focused predominantly on administration functions rather than management functions and as seen from the data, the palliative care programme managers still felt ill-equipped to perform the management role confidently and effectively. This finding supports the need for management training for palliative care managers.

Training needs

One of the objectives of this study was to establish the elements required to provide supervision of community caregivers from the perspective of the palliative care programme managers. This objective evolved during the course of the study to include the elements required to provide supervision of all levels of staff in the patient care team. Palliative care programme managers identified a number of management elements which they felt were relevant to their supervisory role and equated to training needs. These included professional development, human resources, resource management, team dynamics, stress management, advocacy and monitoring and evaluation. These will now be discussed individually in more detail.

Professional development

Professional development was identified as a training need in two ways during the collection of data for this study. Firstly it was identified by palliative care programme managers as a necessity which they themselves require and they identified that they would like to acquire the skills to provide this kind of support to their staff. It was encouraging to find that the palliative care programme managers were able to

identify that their staff may have the same needs as they do and that they are moved to improve their ability to support their staff in this way.

Although several studies have identified the need for professional development programmes in health care in Africa,^(3,4,6,29,32,46) there are significant gaps in the current literature pertaining to the professional development of palliative care programme managers and even the broader scope of health care practitioners working in NPO's in Africa. There is an ideal opportunity for further research especially related to the long –term effects of professional development and the opportunities for improved utilisation of professional development programmes to strengthen health workforces in Africa.

Human resource management

The findings suggest that human resource management skills are essential to palliative care programme manager's ability to supervise the patient care team. There were several human resource functions that were discussed and the data confirms that palliative care programme managers feel insecure in many human resource functions and feel that they would benefit from training in these functions. Furthermore, these findings propose links with all the themes which emerged during data collection. This is understandable as one of the main functions of a palliative care programme manager is to manage the patient care team. Many of their development needs, therefore related to this function.

Firstly, there is the obvious link between human resources and resource management as the patient care team in itself is a resources for the hospice. Secondly, it links with advocacy as there are a number of occasions in the performance of their human resource management function in which they have to advocate including: remuneration and working conditions for their staff; and for their staffing plan and additional human resources for the palliative care programme. Thirdly it links with team dynamics and stress management as it is the palliative care

manager's role to ensure that the patient care team functions optimally and this means ensuring that the staff members are relating to one another optimally and that they are able to effectively manage the stresses related to their job. Fourthly, human resources is linked with monitoring and evaluation from the perspective of palliative care programme managers, because they need to monitor and evaluate their staff in the field and they need to ensure that their staff are recording accurate data for management and funding reports.

Fifthly, the use of the performance appraisal process to identify development opportunities links the theme of professional development with performance management, a human resource function. It has been noted by HPCA palliative care development officers that in general, palliative care programme managers have not yet embraced the performance appraisal as a management tool, but see it rather as *one of those boxes that need to be checked every year*. Perhaps, by seeing the performance appraisal as an opportunity to connect with staff and listen to their difficulties and needs as well as their achievements, strengths and potential, palliative care programme managers may find it easier to support their staff in a way that empowers both the staff member and the manager. This is an interesting opportunity for further research.

It would appear that human resource functions, in general, are daunting for palliative care programme managers and, that they would feel more confident in their position if they were better equipped to deal with these issues.

Resource management

Resource management is an important function of the palliative care programme manager's role and the groups identify it as a needed training topic. This is the only theme that was more dominant in some groups than in others. In South Africa the needs identified regarding resource development involved reporting and presenting these reports whereas in Kenya and Malawi the needs involved resource generation

as well. As mentioned previously, the resources in these two countries are more restricted than in South Africa and in South Africa, most hospices have a fundraising manager and if they do not, this function falls to the hospice manager rather than the palliative care programme manager, which was not reported to be the case by the group participants in Kenya or Malawi. As illustrated by the literature in the literature review, hospices work in an environment where resource limitations are a reality and the need for optimal resource management is essential, it is no surprise then that this theme emerged across the groups and although resource management was discussed with more emphasis in the East African countries included in the study, ideas that are related to and fall under resource management were discussed across the groups.

Team dynamics

Team Dynamics is very important in palliative care as the whole ethos of palliative care is based on a team approach. According to Robert Twycross; palliative care is a holistic care modality based on team work which is best performed by a group of people working as a team and due to the overlap of roles and responsibilities, co-ordination is very important.⁽⁴⁷⁾ It is therefore imperative that the team are able to work together without tension and communication skills, interpersonal skills and conflict management are important functions for palliative care programme managers.

As mentioned above, this is another area in which the themes overlap in that the interdisciplinary team in hospice is a valuable resource and a palliative care programme manager who can use this resource effectively will improve the quality of palliative care delivery at the organisation.

As noted, the patient care team plays an important role in the provision of palliative care and it is the role of the palliative care programme manager to manage this team. The palliative care programme managers in the focus group discussions

expressed a necessity for training in team dynamics and management and this is an important need to address as it affects a fundamental function of their role. It is believed that the palliative care manager's ability to manage her team directly influences the reach and quality of the palliative care service provided by the team. If a palliative care manager can effectively manage her team and assist her professional staff to manage lay caregivers optimally, the team will increase the capacity patients that they can attend to and increase the quality of the service that they render.

Stress management

Stress is an on-going issue in the field of palliative care and palliative care programme managers face not only the stressors of their management function, but also the emotionally taxing nature of patient care in the palliative care setting in Africa. In *Introducing Palliative Care*, Robert Twycross acknowledges that *professional carers have needs too and that palliative care places many stressors on the professional carer*.⁽⁴⁷⁾ It is the palliative care programme manager's responsibility to manage the team's stress and to identify signs of burnout or empathy fatigue in themselves and members of the team.

Again the commonalities in this theme and issues raised in the theme of professional development, resource management and human resources are evident. The discussion platform or forum mentioned in the themes above may also serve as a solution to some of the problems related to stress and burnout.

Monitoring and evaluation

Monitoring and evaluation is important to managers from two perspectives. One, they need to ensure good quality data and statistics and they need to ensure that their staff are being monitored and evaluated.

As previously established, palliative care in Africa is largely NPO run which requires that impeccable data is kept for reporting to funders. The palliative care programme managers related that they battle to control the quality of the data and that they are not using the data optimally in their management function. This fact is corroborated by HPCA palliative care development officers and managers working with hospices in South Africa by means of audits that are done with the hospices.

This theme links with the theme relating to resource management in two ways; firstly hospices require resources in order to manage the quality of their data as pointed out by a participant from Malawi who explained that many sites do not have technical equipment such as computers to capture data. This is a significant problem, because without good quality data, it becomes more difficult to source and retain good funding, a function that is crucial to the sustainability of hospices in Africa.

In monitoring their staff, palliative care programme managers have difficulty in that, in many of the hospice programmes, particularly in South Africa, the caregivers and in some cases, some of the professional staff do not report to the central office at the beginning and end of each day, because the communities that they cover are far from the office and they do not have transport. Palliative care programme managers find it difficult to monitor these staff members and ensure that they are doing the work they are assigned to do. In many cases the professional staff end up having to do spot checks to ensure the work is being done which they feel is a waste of a limited resource, so palliative care programme managers voiced a desire to learn how to monitor and manage the performance of these caregivers more effectively.

It would appear that management styles and principles that encourage accountability and self-monitoring as well as ethical behaviour may be effective in this environment and that palliative care programme managers may benefit from training that includes these styles and principles and how to effectively use them.

Advocacy

The finding concerning advocacy related to advocacy on different levels. Palliative care programme managers advocate for their patients, their staff and for palliative care in many ways. They advocate to policy makers, funders, to senior management and to the board. These managers serve as the voice of palliative care in their regions and advocacy is therefore an essential skill.

Advocacy is a term that is used in many contexts in healthcare and palliative care. Advocating for palliative care to policy makers is a big drive in all the countries mentioned. Palliative care is a fairly new discipline in Africa and government health departments do not always acknowledge it as a bona fide field of medicine and subsequently funding allocation for palliative care is sparse and very often it is included in the budgets of other much bigger fields so the actual budget allocation for palliative care is very small and totally inadequate to address the needs as highlighted in the literature review.

Not only do palliative care health workers have to advocate for funding, but in several African countries, access to morphine is severely restricted or even illegal and pain control in palliative care requires the use of morphine. Advocating for policy change is therefore necessary and palliative care programme managers would benefit from training and development of this skill.

On a more modest level, palliative care managers advocate every day for quality palliative care, for resources, for their patient's needs and for their staff's needs. All of which have no lesser effect than advocacy at the level of policy makers and funders.

Support measures

Two of three main themes identified by palliative care managers as professional development needs took the form of supportive measures. Measures to support their training and development and sustain them in their role as palliative care programme managers; professional development and palliative care training for doctors and non-clinical staff and managers.

Professional development

The findings of this study purport that professional development in the form of supportive mentorship and coaching programmes and supervision as well forums or discussion groups is needed by palliative care programme managers across the regions in all three countries.

The focus group discussion data suggested that palliative care programme managers lack the required support that they need to make the transition from hands on care to management and to sustain them in their role as managers. In reviewing the literature, it was noted that health care professionals across Africa are experiencing significant role change and/or task shifting with little or no support for this transition.^(21, 24, 26, 27) The data from the survey which shows that more than 80% of the respondents rated their need for support above the average rating is consistent with the focus group data and the literature.

In addition there is literature to support the effectiveness of mentorship and coaching programmes in healthcare, but there is a gap in the literature regarding programmes in healthcare NPOs in Africa. This would suggest that this potential form of support to the health workforce is being under-utilised in this context. An additional gap in the literature regards evidence of long-term benefits of these programmes.

In relation to the palliative care manager's need for support and professional development, the idea of a forum or similar platform to discuss palliative care

programme management issues was discussed, if this were to be followed through, it may prove to be an ideal means to sustain palliative care managers. This kind of discussion platform or forum would also allow for better co-ordination of palliative care services and training and development in the regions.

The logistics of the discussion groups or forums were not discussed and as many of the palliative care programme managers work in rural settings and may not have the resources to travel the long distances to meet regularly, the idea may be abandoned as it may be felt that it is not feasible, but perhaps these forums could take on a more virtual form. An interactive blog or Skype meetings may serve the same purpose without the resource and logistical problems associated with meeting on a regular basis.

A key issue which emerged across the region was that palliative care programme managers need support. The implications of this data are that measures need to be implemented to provide on-going training and skills development for palliative care programme managers as well as support programmes

Palliative Care Training

The researcher had assumed that palliative care training within the palliative care field would be readily available and that most people working in the field would have had palliative care training, but two main issues regarding palliative care training were voiced across the focus groups. These included concerns regarding the lack of palliative care knowledge of doctors working with hospice patients and the lack of knowledge of non-clinical staff and managers working in hospices.

There is great effort being made to increase the availability of palliative care training in Africa, but to date, it is still very difficult for those in rural Africa to access this training. It is anticipated that the results of this research will add weight to the advocacy strategies to make palliative care training more readily accessible in Africa.

Palliative care programme managers were concerned that some of the doctors that they work with in caring for hospice patients had little or no knowledge of palliative care principles and they felt that this impacted the quality of care that they received. They also spend time, a valuable resource, advocating for palliative care with these doctors and this time could be better spent if the doctors were trained and better working relationships could be developed.

Palliative care training for non-clinical staff and managers was identified as a need as the palliative care programme managers felt that a lack of understanding of the work that is being done by the patient care team leads to unnecessary conflict. In the focus group discussions, it was pointed out that if the fundraiser and administrative staff understood the nature of the work being done in the field, they would not source and acquire inappropriate equipment and resources. This would lead to more optimal sourcing and use of resources and less conflict among staff.

Palliative care training for the doctors and non-clinical staff and managers will give them a better understanding of the work that is being done and allow them to support the palliative care managers and the patient care team more effectively.

Limitations of this study

This study had a number of limitations.

The objective to assess the patient care managers' perception of the essential elements of quality palliative care was inferred from the study rather than being directly examined. Palliative care programme managers identified the development needs from a position of experience and understanding of the essential elements of quality palliative care. A number of these elements were discussed during the focus group discussions including: an holistic approach, team work and quality care.

The information which initially informed the decision to investigate the professional development needs of patient care managers, namely the views verbalised at the CIDA workshops, was not documented at the time and this meant that the initial hypothesis was based on verbal testimony rather than documented evidence. Documentation of this initial data would have helped to concretise the triangulation of data and would have leant weight to the resulting data collected from this study.

The author also believes that additional depth could have been added to the data and triangulation of data would have been enhanced if the development needs section of the performance appraisals of the palliative care programme managers working in hospices had been studied and analysed alongside the data from the surveys and focus group discussions. This omission allows for further research and testing of this study in future.

Due to the fact that numerous ethical bodies had to be consulted, the ethics approval process was very time consuming and better coordination of this process by the author would have allowed more time for the data collection process.

The number of participants who completed the on-line survey was lower than anticipated and those who did complete it were predominantly from South Africa. For generalizability, of the data, it would have been preferential to have participants from the East African countries verify that the focus group discussions done in their countries had in fact identified and represented their professional development needs.

Conclusion

The findings of this study support the original hypothesis that palliative care programme managers require professional development and support. This is substantiated by the literature which also illuminates the fact that there is a gap in current research and that research regarding professional development in healthcare NPOs in Africa is needed.

The trustworthiness and credibility of these findings was ensured by the fact that the data was collected from different sources in different ways. These finding were also validated by the pilot training course that was run to test the curriculum and training material that was developed from the findings of this study.

Chapter six

Conclusion and Recommendations

Conclusion

The study aimed to explore the need for professional development of palliative care programme managers in hospices in Kenya, Malawi and South Africa so that a specific and comprehensive curriculum with supporting training material could be developed. This was done in response to a need that was identified by HPCA managers who ran a series of regional workshops for CIDA in 2009.

The author wanted to establish if the need identified was a real need and to get input from palliative care programme managers in the field as to how best to address this need if it existed. Focus group discussions held in Kenya, Malawi and South Africa revealed that there was indeed a need for professional development in the form of mentorship and coaching, a support network or forum and training. The author used the data from the focus group discussions to develop a survey which was structured in such a way as to establish if the needs identified by the focus group discussions translated to the greater palliative care programme manager population and this data served to corroborate the data that was gleaned from the focus group discussions.

The data from both the focus group discussions and the surveys clearly indicated a need for professional development as defined above. Participants agreed that support in the form of a forum as well as mentorship and/or coaching would be beneficial to them in their working environment. Participants also identified a number of training topics that would help them to improve their management function, namely: professional development, human resource development, resource development, stress management, advocacy and marketing, team dynamics and; monitoring and evaluation.

As a result of this needs assessment that was done and the findings thereof, HPCA formulated a task team to work with the author to use the above data to develop a curriculum and training material which would potentially address the specific professional development needs of the palliative care programme managers involved in the study as well as all other palliative care programme managers working in hospices in Kenya, Malawi and South Africa.

From the literature review, it was clear that very little research has been done to determine the development needs of palliative care programme manager's working in hospices in Africa and this research was done so that the relevant bodies in each of the countries involved could use the collected data to design a professional development programme that is relevant and appropriate.

The author believes that providing appropriate training and support to palliative care programme manager's, organisations can improve the productivity and job satisfaction of palliative care programme managers in hospices and that by equipping these professionals to cope with higher numbers of staff and caregivers, they will provide quality care to higher numbers of patients and thereby increase the reach of palliative care in Africa. It was also believed that this would allow hospices to provide more financially lucrative packages as the number of professionals needed to run hospice home-based-care programmes will be reduced because palliative care programme manager's will be better equipped and more efficient.

By including participants from different regions in the three countries, the author believes that this study has managed to, more accurately, identify the professional development needs of palliative care programme managers working in hospices in South and East Africa and in so doing, has been able to inform an HPCA task team which was developed a comprehensive training curriculum and professional development plan that will address the specific needs of this group. The author believes that this research directly supports the WHO initiative to *Increasing Access to Health Workers in Remote and Rural Areas*, because by developing palliative care programme managers who work in hospices, to better manage professional and lay

staff, the author believes that the quality and reach of these hospice programmes will be expanded. A belief that is supported by Johnson et al who state; “Human Resource Development(HRD) can play a role in exploring ways to help increase the capacity and reach of trained health care workers at the community level.” They go on to say that; “South Africa is well positioned to play an influential role in how HRD connects with grassroots NGOs and National HRD efforts to turn the tide on this health and human resource development crisis.” The author hopes that data from this study will inform the National HRD efforts mentioned by Johnson et al.

The author believes that; it is imperative that the findings of this research are used optimally. The author has therefore, made every effort to ensure that the findings of this research will be used to empower palliative care programme managers in hospices in Kenya, Malawi and South Africa. The data has been disseminated by means of report-back to all participants and organisations by means of a report as well as a presentation at the HPCA conference in Cape Town in September 2012. The author also intends to submit an article for publication in academic journals.

Outcomes

At the time of completion of this dissertation, a number of the expected outcomes for this study had been achieved. They have been mentioned below and a further detailed explanation is available in addendum I.

In line with the expected outcomes of this study, the findings have been used by an HPCA task team, which includes the author, to develop a training curriculum and training material; and a pilot training course was presented to representatives from the target regions in Kenya, Malawi and South Africa in October and November of 2012. Feedback from this pilot training course helped to validate the findings of this study and it was used to review the curriculum and the training material and it is

intended that the representatives that attended the pilot training course will disseminate the training to their regions during the course of 2013.

The findings were also used to develop a new job profile for future palliative care programme manager appointees. This was done in collaboration with representatives who attend the pilot training course mentioned above.

Development of curriculum and training material

At the time that this dissertation was written, a curriculum and training material had been developed and piloted and reviewed. This curriculum was developed in collaboration with an HPCA task team, members of which were chosen for the task team so that there would be a distribution of expertise which included human resources, education, professional development and palliative care.

Based on the themes identified in the assessment part of this study, a curriculum that included the following topics was developed: Personal ethics and values, Applied Emotional Intelligence and Coaching and Mentorship, Time management, Concept of management and styles, Role of Patient Care manager, Job profiles, Performance management, Managing resources, Strategic planning, Risk management, Communication, Patient review and optimal care, Data management, Conflict management, Team dynamics, Report writing, Legislation

The curriculum was designed to fit into two sessions. The first session would be held over three days and the second over two days, and they would be held one month apart. The course was designed in this way as it was felt that five full days is a long time for palliative care programme managers to be away from their organisations and the time between the two sessions would allow the participants to begin to assimilate the course content before the second session began. The second session would also allowed the participants the opportunity to follow up with the course

facilitators and ask any questions that may have come up after they left the first session.

After each of the training sessions, participants were given evaluation forms to fill in regarding the content and structure of the training. Feedback from the pilot training course was reviewed and the curriculum and training material were adjusted in line with the feedback. Feedback regarding the content of the course was very positive and predominantly comments suggested increasing or decreasing the amount of time spent on topics or the level of depth given to the topics and there were no topics that were considered irrelevant and no topics that the participants felt needed to be added. See addendum I for the reviewed curriculum.

In general, the feedback related to the structure of the course and this feedback was considered and reviewed and the curriculum and training material adjusted. The team spent time assessing the evaluation forms and decided to restructure the curriculum so that it comprised of themed days. This change was made for the following reasons:

- The team felt it would give the curriculum a better flow
- This structure meant that the training would be more flexible for roll out as it could be rolled out in its entirety or as individual day sessions depending on which was more appropriate for the group.
- This change also allowed the team to give more time and depth to those topics that needed it such as the emotional intelligence topic and performance management.

An additional change that was made was that two of the modules were aligned to unit standards. In the review discussions the team decided to align two of the modules with unit standards, because aligning the modules with unit standards would allow the team to pursue potential accreditation of the course in the future. The first module that was chosen to align with the unit standards was the module on

report writing which was expanded to include presenting and the second was a section of the module on emotional intelligence, the mentorship and coaching section.

Roll out for the reviewed training material is scheduled in the Gauteng region in March of 2013.

The Job profile

Another intended outcome for this study was the development of a Job profile for the palliative care programme manager's position. The example job profile that is given in addendum I was developed as a class exercise during the pilot training course. The class was divided into groups and asked to put together a job profile. All the profiles were then collated by the author to create an example job profile which can be used by organisations to match ideal candidates to the position.

Recommendations

Based on the findings of this research, the following recommendations are made:

- Palliative care programme managers should be offered the opportunity to attend training sessions/courses which include topics from the identified needs such as the *Introduction to Management for Palliative Care Programme Manager's* course which was developed by HPCA in line with the study findings.
- Palliative care programme managers should be offered some form of mentorship or coaching so that they can get the necessary support to set measurable goals and targets for their programmes and their development and receive focused and structured support to achieve these goals.

- Forums or discussion groups should be formed within the regions to support the palliative care program managers. As discussed earlier, this may be done in the form of interactive blogs or Skype meetings if physical meetings are not feasible.
- Potential palliative care programme managers should meet the minimum requirements for the job profile that has been developed in line with findings of this study.

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Addenda

Addendum A: Interview guide – Focus Group Discussions

Focus group discussion questions:

- What pre-service and in-service preparation have you had for supervising community caregivers?
- What skills do you feel palliative care programme managers should have for supervising community caregivers?
- What do you feel are the essential elements of quality palliative care?
- What mentorship resources are available to you?

Addendum B

Information sheet for phase 1 of the below-mentioned research project:

Evaluation of development needs of professional healthcare personnel in the context of providing quality palliative care to increasing numbers of patients in Kenya, Malawi and South Africa

My name is Susan McGarvie. I work for the Hospice Palliative Care Association of South Africa. I am doing my Master of Philosophy degree in Palliative Care through the University of Cape Town. I am doing a research study to determine the development needs of Palliative care programme managers in hospices, which I hope will help to develop a training programme that is specifically suited to the needs of the Palliative care programme managers in hospices.

The results of the study will be reported back to all the organisations involved. They will also be published in a peer-review journal and presented at appropriate conferences. No names will be used in the final write up and participation will be kept confidential. This research will be funded by the Princess Diana Foundation.

The research study will be done in two phases. Phase 1 will be done by means of focus group discussions in Kenya, Malawi and South Africa. There will be a pilot focus group and two additional focus groups held in South Africa. One focus group will be held in both Kenya and Malawi. 8-10 people will participate in each focus group. Phase 2 will be done by using the data that is collected during the focus group discussions to develop a survey which will then be sent to all the member hospices in Kenya, Malawi and South Africa.

Please be aware that your participation is entirely voluntary and there will be no reprisals should you decide not to participate. The decision to participate is yours entirely. If you decide to participate, you may pull out at any time. Should this process upset you in any way, counselling will be provided through your own organisation. All participants will be required to sign two consent forms: one to consent to participation and one to consent to the focus groups being video'd.

The focus group discussion will last approximately one hour and will take the form of a group discussion guided by a few questions. You will not be forced to participate at any time, but your thoughts would be appreciated and participation in the discussion is encouraged.

The data will be stored on CD/DVD and kept securely by the author for two years if the results are published and for six years if the results are not published. Only the members of the research team will have access to the information.

If you have any other queries about the study, you may contact Dr Pat Mayers or Dr Liz Gwyther

If you have any queries or complaints about any aspects of the research study, you may contact Prof M Blockman who is the manager of the Human Research Ethics Committee at the University of Cape Town and /or Cheryl Borreson at the HPCA ethics committee.

Contact details:

Prof M Blockman

Research Ethics Committee

Tel: 021 406 6338

Fax: 021 406 6411

Room E52.23

Old Main Building

Grootteschuur Hospital

Cape Town

email: nosi.tsama@uct.ac.za and shuretta.thomas@uct.ac.za

Cheryl Borresen

HPCA Ethics Committee

Tel: 031 261 7868

email: cborresen@iburst.co.za

Dr Liz Gwyther

11a Lonsdale Building

Lonsdale Way

Pinelands, 7430

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Tel: +27-21-5310277

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Cell: +27-83-6516294

Associate Professor Pat Mayers

Division of Nursing and Midwifery

School of Health and Rehabilitation Sciences

Faculty of Health Sciences, UCT

F45 Old Groote Schuur Building

Observatory 7925 Cape Town

Tel: +27214066464

Departmental Fax: +27214066323

Email: Pat.Mayers@uct.ac.za

Addendum C

Information sheet for phase 2 of the below-mentioned research project:

Evaluation of development needs of professional healthcare personnel in the context of providing quality palliative care to increasing numbers of patients in Kenya, Malawi and South Africa

My name is Susan McGarvie. I work for the Hospice Palliative Care Association of South Africa. I am doing my Master of Philosophy degree in Palliative Care through the University of Cape Town. I am doing a research study to determine the development needs of Palliative care programme managers in hospices, which I hope will help to develop a training programme that is specifically suited to the needs of the Palliative care programme managers in hospices. This research is being funded by the Princess Diana Foundation.

The research study has been done in two phases. Phase 1 of the study was done in the form of focus group discussions in Kenya, Malawi and South Africa. Phase 2 is being done by using the data that was collected during the focus group discussions to develop a survey which is now being sent to all the member hospices in Kenya, Malawi and South Africa.

As mentioned above, this phase of the study is being done by means of a survey. The survey is a short survey of 5-10 questions that should take no longer than 1 hour to complete. The survey has been developed from the information that was gleaned from the focus group discussions and is being sent to 250 participants.

If you have any other queries about the study, you may contact Dr Pat Mayers or Dr Liz Gwyther at the University of Cape Town.

If you have any queries or complaints about any aspects of the research study, you may contact Prof M Blockman at Human Research Ethics Committee at the University of Cape Town.

Contact details:

Prof M Blockman
Research Ethics Committee
Tel: 021 406 6338
Fax: 021 406 6411
Room E52.23
Old Main Building
Groote Schuur Hospital
Cape Town

email: nosi.tsama@uct.ac.za and
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Dr Liz Gwyther
11a Lonsdale Building
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e-mail liz@hpca.co.za
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Associate Professor Pat Mayers
Division of Nursing and Midwifery
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Faculty of Health Sciences, UCT
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Departmental Fax: +27214066323

Email: Pat.Mayers@uct.ac.za

Addendum D

Consent form for Phase 1 of the following research project:

Evaluation of development needs of palliative care programme managers in the context of providing quality palliative care to increasing numbers of patients in Kenya, Malawi and South Africa

I the undersigned, acknowledge that I have read and understood the attached information sheet regarding the aforementioned research project and willingly consent to participate.

I have had the opportunity to ask questions and have had these satisfactorily answered.

I understand that my participation is voluntary, that my personal information will be kept confidential beyond the research team and that I can withdraw at any time without fear of penalty.

Date: _____

Name of participant: _____

Signature of participant: _____

Witness 1: _____

Witness 2: _____

Name of person taking informed consent: _____

Signature of person taking informed consent: _____

Date of informed consent:

Addendum E

Dear Sir/Madam

I am writing to ask permission to do a study at your organisation involving your professional healthcare personnel. The study will require that your professional healthcare personnel participate in a one hour focus group discussion regarding the development needs of professional healthcare personnel in hospices. (Please see attached information sheet)

After the data from the focus group discussions has been collected and analysed, a short survey will go out to all member hospices so as to deepen the quality of the data.

The author has been granted ethics approval from the University of Cape Town's ethics committee as well as the Hospice Palliative Care Association's Research Ethics Committee in South Africa and the _____ ethics committee in your country.

I thank you for considering participation in the study.

Yours faithfully

Susan McGarvie

Tel and/fax: 046 6241730

Cell: 082 574 7556

Barville Park Farm

P.O. Box 270

Port Alfred

6170

Addendum F

Consent form for video permission for Phase 1 of the following research project:

Evaluation of development needs of palliative care programme managers in the context of providing quality palliative care to increasing numbers of patients in Kenya, Malawi and South Africa

I understand that the process that I have consented to participate in, namely phase 1 of the above mentioned research project, will be recorded on video and consent to said video being used for research purposes. I am aware that the research team will have access to the video recordings and consent to this access.

I have had the opportunity to ask questions and have had these satisfactorily answered.

I understand that my participation is voluntary, that my personal information will be kept confidential beyond the research team and that I can withdraw at any time without fear of penalty.

Date: _____

Name of participant: _____

Signature of participant: _____

Witness 1: _____

Witness 2: _____

Name of person taking informed consent: _____

Signature of person taking informed consent: _____

Date of informed consent:

Addendum G

Ethics Committee Approval Letters

Telephone: + 265 789 400
Facsimile: + 265 789 431

All Communications should be addressed to:
The Secretary for Health and Population



In reply please quote No. MED/4/36c
MINISTRY OF HEALTH AND POPULATION
P.O. BOX 30377
LILONGWE 3
MALAWI

30th November 2010

Susan Mc Garvie
University of Cape Town

Dear Sir/Madam,

Re: Protocol # 806: Evaluation of the development needs of professional health care workers in the context of providing quality palliative care to increasing numbers of patients in Kenya, Malawi and South Africa

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review.

Please be advised that the NHSRC reviewed the proposal and agreed that the Study may be approved **through expedited process** after addressing the following concerns:

- Delete word "Evaluation" in the title of the study and replace it with "Exploration"
- Clarify what the questionnaire will be used under phase two. Is it for individual interview?
- When the questionnaire will have been developed, it will have to be submitted to the committee for review
- One FGD in Malawi would not yield the required information.

Kind regards from the Secretariat.

FOR: CHAIRMAN, NATIONAL HEALTH SCIENCES
RESEARCH COMMITTEE

Suite 11a, Lonsdale Bldg, Lonsdale Way, Pinelands 7405
P O Box 38785, Pinelands, 7430, South Africa
Tel: 021 531 0277 Fax: 021 531 1706
Email: hpc@iafrica.com
www.hospicepalliativecaresaco.za



10 August 2011

Ms S McGarvie
Hospice Palliative Care Association
Susan@hpc.co.za

Dear Ms McGarvie

PROTOCOL : Evaluation of the development needs of professional healthcare workers in the context of providing quality palliative care to increasing numbers of patients in Kenya, Malawi and South Africa. S McGarvie, HPCA, CT. Ref. 02/11

The above protocol was reviewed by the Hospice Palliative Care Association Research Ethics Committee at its meeting held on 24 May 2011. Queries raised have now been addressed and the protocol is given full ethics approval.

The following documents have been approved :

Application to Conduct Research : 2011 – as submitted on 11 July 2011;
Addenda A – J – as submitted on 8 August 2011.

Please note the following :

- An original signed copy of the amended protocol and supporting documentation (as approved) must be submitted to the HPCA offices in Cape Town.
- Ethics approval is valid for one year only;
- Application for recertification of the protocol should be submitted a couple of months prior to the 24 May 2012 to ensure continuous approval;
- ANY changes to an approved protocol must be reviewed by the Research Ethics Committee.

It would also be appreciated if, once the study has been completed, a summary of the results could be submitted to the REC for inclusion on the HPCA web-site.

I would like to take this opportunity to wish you well with your research.

Yours sincerely

PROFESSOR A DHAJ
Chair : Hospice Palliative Care Research Ethics Committee
Reg. No. : REC-250408-005

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Palliative Care is an approach that improves the quality of life of patients and their families facing life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

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S Mogotlane, C Mokatsane, E Scrimgeour, T Thompson, R Wienekus, M Wollheim
E Gwyther (CEO), K Henning (COO), C Hodgskiss (CFO) J. Lazarus (Company Secretary)



UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6626 • Facsimile [021] 406 6411
e-mail: shuretta.thomas@uct.ac.za

23 August 2010

HREC REF: 364/2010

Ms SL McGarvie
c/o Dr P Mayers
Public Health & Family Medicine

Dear Ms McGarvie

PROJECT TITLE: EVALUATION OF THE DEVELOPMENT NEEDS OF PROFESSIONAL HEALTHCARE WORKERS IN THE CONTEXT OF PROVIDING QUALITY PALLIATIVE CARE TO INCREASING NUMBERS OF PATIENTS IN KENYA, MALAWI AND SOUTH AFRICA.

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Approval is granted for one year till the 30th August 2011.

Please change the contact person on the Information Sheet to participants to be Prof Marc Blockman as chair: UCT Human Research Ethics Committee.

Please submit an annual progress report if the research continues beyond the approval period. Please submit a brief summary of findings if you complete the study within the approval period so that we can close our file.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

S Thomas

Yours sincerely

Oliver Henley

PROFESSOR M BLOCKMAN

CHAIRPERSON, HSE HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

S Thomas

Susan Mcgarvie

From: Nairobi Hospice - Clinical Dept. <clinical@nairobihospice.or.ke>
Sent: 30 March 2012 10:32 AM
To: Susan Mcgarvie
Cc: zippy@kehpca.org
Subject: RESEARCH PROPOSAL

Dear Susan,

Thanks you for your request to carry out the study - **"Evaluation of the development needs of professional healthcare workers in the context of providing quality palliative care to increasing numbers of patients in Kenya, Malawi and South Africa.** You application was forwarded to the Ethics Committee at the Nairobi Hospice and has been approved. The committee requests that on completion of the study you should forward a report on the findings. Please let me know the exact dates you will be visiting the Hospice.

Regards

Dr. Michelle Muhanda
Senior Medical Officer
Nairobi Hospice
P.O. Box 74818-002, Nairobi
Tel. +254 20 2712361, +254 20 2719383, +254 20 2726502
Fax +254 20 27222212
Website: www.nairobihospice.or.ke

Vision

The Nairobi Hospice aims to be a leading, sustainable, training, research and consultative institution in Kenya providing and promoting quality and cost effective palliative care.

Mission

To alleviate the suffering of patients with life limiting illness and their families, through commitment to service, counseling, training and advocacy

Addendum H

Copy of the on-line survey

This survey can also be found at: <https://www.surveymonkey.com/s/RSCZ73G>

This survey relates to the following research project: Exploration of the development needs of professional healthcare workers in the context of providing quality palliative care to increasing numbers of patients in Kenya, Malawi and South Africa. This research is being done for HPCA and the Diana Princess of Wales foundation.

1. What is your name?

What is your name?

2. What is the name of your organisation?

What is the name of your organisation?

3. In which country is your palliative care organisation situated?

- ☐ Kenya ☐ Malawi ☐ South Africa

4. If your palliative care organisation is not situated in South Africa, how long has it been established?

If your palliative care organisation is not situated in South Africa, how long has it been established?

5. What sort of area does your organisation cover?

- ☐ What sort of area does your organisation cover? rural
☐ urban

6. Category of organisation:

- ☐ Category of organisation: 1 star
☐ 2 star
☐ 3 star

- ☐ 4 star
- ☐ 5 star
- ☐ Site outside of South Africa

7. What is your profession?

- ☐ What is your profession? medical doctor
- ☐ professional nurse
- ☐ social worker
- ☐ Other (please specify)

8. What role do you play in your organisation with regard to management?

What role do you play in your organisation with regard to management?

9. Have you had any management training?

- ☐ Have you had any management training? yes
- ☐ no

10. If you answered yes to the previous question, what type of management training have you had?

- ☐ management module as part of your clinical training
- ☐ post graduate training in management
- ☐ HPCA LDP course

Other (please specify)

Please read the questions below and rate them from 1 to 5, where 1 is not at all relevant to you and 5 is very relevant.

11. During the course of your work as a patient care or clinical manager do you feel you would benefit from support in the form of a management mentorship programme that includes regular mentorship or coaching sessions and forum meetings to discuss management issues?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

12. Do you feel that the organisation in which you work would function more optimally if more of your non-clinical staff and managers had basic palliative care training?

- ☐ 1
☐ 2
☐ 3

- ☐ 4
☐ 5

Please indicate if you feel that you would benefit from training in any of the following subjects. Again, please rate these from 1 to 5.

13. Professional development which includes: coaching/mentorship skills, leadership skills, needs assessment training, training skills, and counselling skills.

- ☐ 1
☐ 2
☐ 3

- ☐ 4
☐ 5

14. Human resource management which includes: performance management, staff planning, human resource legislation

- ☐ 1
☐ 2
☐ 3

- ☐ 4
☐ 5

15. Resource management which includes: resource mobilisation, project management, proposal and report writing and networking

- ☐ 1
☐ 2
☐ 3

- ☐ 4
☐ 5

16. Stress management which includes: resilience training and time management

- ☐ 1
☐ 2
☐ 3

- ☐ 4
☐ 5

17. Advocacy and marketing

- ☐ Advocacy and marketing 1
☐ 2
☐ 3

- ☐ 4
☐ 5

18. Team dynamics which includes team mobilisation, communication and conflict management

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

19. Monitoring and evaluation

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

20. Please indicate if there is anything not mentioned above that would assist you in your management function.

Please indicate if there is anything not mentioned above that would assist you in your management function.

Thank you for your participation in this survey.

Next

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Addendum I

Job Profile: Patient Care Programme Manager

Job Description

Job Title: Patient Care Programme Manager

Responsible to: Hospice Manager

Aim of the job: To manage a quality palliative care programme

Key Performance Area	Duties
Patient care management	<ul style="list-style-type: none">• Manage the development and maintenance of all patient care and related policies• Plan, coordinate and supervise patient care programme• Manage Risk and Quality<ul style="list-style-type: none">○ Manage the development and maintenance of risk and quality plans○ Ensure that quality improvements projects are initiated and completed in line with the quality management plan○ Ensure that file and clinical audits are done regularly
Human Resource Management	<ul style="list-style-type: none">• Develop a staffing plan for the patient care team in line with the organisation's staffing plan, strategic plan and budget• Liaise with HR management staff to ensure the development and maintenance of HR policies and procedures• Liaise with HR staff to ensure that the team is managed in accordance with current legislation• Manage the recruitment, appointment, orientation and retention of the appropriate staff to run the programme efficiently• Manage the performance of the team• Manage conflict
Strategic management	<ul style="list-style-type: none">• Participate in the development of organisation's strategic plan

	<ul style="list-style-type: none"> • Manage the development of a strategic plan for patient care which is aligned with the organisation's strategic plan, HR plan and budget
Financial management	<ul style="list-style-type: none"> • Participate in the development of the organisation's budget • Manage the development of a budget for patient care which is aligned with the organisation's budget • Manage the adherence to the budget
Administration	<ul style="list-style-type: none"> • Planning and management of stock • Reporting to the board, funders and other stakeholders • Monitoring and evaluation <ul style="list-style-type: none"> ○ Ensure that staff are trained to collect data correctly ○ Ensure that data quality audits are done regularly ○ Ensure that statistics and reports are submitted to all the relevant bodies by the due dates
Training	<ul style="list-style-type: none"> • Plan and coordinate training for patient care staff according to identified training needs • Provide time, resources and support for patient care staff to attend training
Networking and partnerships	<ul style="list-style-type: none"> • Develop and foster networking relationships and partnerships with relevant stakeholders in the community
Advocacy	<ul style="list-style-type: none"> • Advocate for palliative care services in the community • Advocate for patients • Advocate for staff
Resources management	<ul style="list-style-type: none"> • Contribute to funding proposals as required • Ensure that all hospice resources are used optimally and in line with policies and procedures • Manage procurements in line with policies and procedures • Ensure that all stock is managed

	according to policies and procedures
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Limitations/Scope of practice:

The patient care programme manager must have the following:

- An appropriate humanities/medical qualification
- A valid registration with the appropriate professional body
- A valid driver's licence and own transport

Work conditions, environment and equipment:

- Patient care programme manager will be provided with an office and a computer with internet connection
- Travelling for work will be required

Job specifications

Qualifications:

- Appropriate health related qualification
- Palliative care training

Experience:

- At least five year's experience in palliative care
- Management training and/or experience

Competency profile:

- Self directed
- Team leader
- Emotionally intelligent
- Organised

Skills:

- Management skills
- Computer literate
- Training and mentorship skills
- Good communication skills

Attitudes:

- Positive attitude
- Open-minded
- Determined

Physical requirements:

- Energetic
- Physically fit

Language and Communication:

- English required
- Local language beneficial

Special abilities:

- Palliative care management

Employment equity:

- This position is filled in line with the organisation's employment equity policies and current legislation

Update and file reference:

Signature of Employee _____

Date _____

Signature of Manager _____

Date _____